Imogen Blood &
Associates

In partnership with
Innovations in Dementia

ACT ON DEMENTIA

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Co-funded by
the Health Programme
of the European Union

Evidence Review of Dementia Friendly Communities

European Union Joint Action on Dementia

17 August 2017

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Abbreviations used in this report

BBC – British Broadcasting Corporation
DEED – Derry Engages & Empowers Dementia
DEEP – Dementia Engagement & Empowerment Project
DFC – Dementia Friendly Community
DFCs – Dementia Friendly Communities
EU JA – European Union Joint Action on Dementia
EU – European Union
EWGPWD – European Working Group of People with Dementia
FIT – Face It Together
GPS – Global Positioning System
IiD – Innovations in Dementia CIC
IPC – Institute of Public Care (Oxford Brookes University)
LGA – Local Government Association (UK)
MoMA – Museum of Modern Art
PWD – People with Dementia
SURF – Service User Review Forum
SURP – Service User Review Panel
TV – Television
UK – United Kingdom
VU – Vrije Universiteit Amsterdam
WP7 – Work Package 7

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EXECUTIVE SUMMARY

Background
This report presents the findings of an evidence review conducted by Imogen Blood & Associates in partnership with Innovations in Dementia to inform Workpackage 7 of the EU Joint Action on Dementia, which is being led by the English Government (Department of Health). The review aimed to:

- Identify best practice examples in relation to the development of Dementia Friendly Communities (DFCs);
- provide a definition of DFCs,
- Identify the components of an effective DFC: arriving at a model demonstrating the key success factors of a DFC, synthesizing data from interviews, group discussions, online survey feedback, and key components of other existing models; and
- Develop a set of indicators to test the success of the forthcoming pilots within this Workpackage.

The report is based on the following primary and secondary evidence:

- 82 reports and articles identified through a systematic search for international published and 'grey' literature;
- Three group discussions with people with dementia, including the European Working Group of People with Dementia and two groups within the Dementia Engagement and Empowerment Project network in England;
- 20 interviews with 25 participants with people involved in DFCs from a total of 10 countries across the EU, including two visits to DFC projects in the UK.
- An online survey, sent out to EU dementia leads and contacts, to which 57 responses were received.

The report is structured around the 'four cornerstones' model, which has been used in the evaluation of several DFC initiatives in the UK. The four 'cornerstones' are: People, Place, Networks and Resources.

Definition
There are a number of contests in relation to the concept of a 'Dementia Friendly Community' and each of its component terms. Various existing definitions have been reviewed within this study and feedback gathered on them via the online survey. Based on this, the team proposes the following definition:

> In a 'Dementia Friendly Community', people with dementia are included and respected. Citizens, organisations and businesses work together to remove the barriers which stop people with dementia and their supporters from participating in community life.

DFCs are an ongoing process of learning and culture change, rather than a state. The activities and detailed structure of DFCs need to be defined locally and informed by local residents who are living with dementia and their care-givers.

People

This section demonstrates that the awareness and acceptance of other people is a key enabler of a DFC. The review has identified a number of barriers which people with dementia and their supporters encounter in their social relationships and day-to-day encounters with other people.

DFCs may include various activities aimed at changing people's attitudes and behaviours towards people with dementia, including:

- Awareness raising – through awareness raising or more formal training sessions, use of media, and intergenerational work;
- Opportunities for people with dementia and their carers to make a contribution, through voluntary work, including but not limited to providing peer support;
- One-to-one support to people with dementia to help them to access mainstream community life.

Based on the evidence reviewed, the authors recommend that these activities:

- Involve people with lived experience in developing and delivering awareness raising activities and products;
- Focus on practical adjustments and communication skills;
- Are made specific to the roles of people working in different settings, wherever possible; and
- Create and emphasise the importance of opportunities for people with dementia to participate in and contribute to mainstream community life (i.e. not just in separate, specialist activities).

Place

Asserting the rights of people with dementia to access 'everyday' public spaces should be a core value of DFCs. People with dementia and their supporters identify a range of barriers to accessing indoor and outdoor public spaces, including: poor signage, inaccessible public transport, lack of toilets, complicated layouts, disorientating flooring and complex information and processes.

The evidence suggests that effective DFC initiatives in relation to place:

- Involve people with dementia and their carers in auditing the accessibility of places, information and systems;
- Train staff in the 'public realm' – transport workers, police, staff at public venues and customer-facing businesses;
- Work to facilitate way-finding and reduce sensory overload;

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- Create safe spaces for people with dementia and their carers to meet and mix, but also support the integration of people with dementia into mainstream clubs, organisations and services.

Networks

In order to establish an effective DFC, the evidence suggests it is important to:

- Establish a broad network, including partners from a range of businesses and services (i.e. not just health and social care), who can share responsibility for different work streams and actions. Ensure general health services (i.e. not just those with a dementia specialism) are engaged;
- Consider the size of the area: DFC initiatives seem to be most effective when they focus on relatively small communities, though local action can be coordinated strategically at a city or regional level;
- Face-to-face outreach and personal networking is an effective way of engaging shops and businesses but it can be very time-consuming and is more powerful where there is a personal connection to dementia and/or people with dementia and their supporters are directly involved;
- A multi-media approach, which might include local TV, radio and newspapers, leaflets, posters, public meetings and personal networking, seems to be most effective;
- Ensure the voices of diverse people with dementia and their carers are heard within this network or alliance. There are several different ways of doing this, including:
  o Making the alliance or network meetings and decision-making processes accessible to people with dementia;
  o Supporting individuals to attend or feed in their views outside of meetings;
  o Developing a parallel advisory group of people with dementia which feeds into the alliance in a structured way.
- Recognise that people with dementia may need support and education if they are to participate meaningfully and if diverse voices (especially in relation to the stage of the condition and socio-economic status) are to be heard.

Resources

- DFCs receive a huge range of financial resources: some 'grassroots' efforts run entirely on voluntary effort; others receive funding from government/ national charities
- Time, energy and leadership are the key resources, though the input of people with dementia requires some funding if it is to be effective and sustainable;
- In some countries, a national charity (sometimes with government funding) is supporting a network of DFCs, providing them with: publicity and awareness-raising materials, branding, guidance, mechanisms for sharing learning, awards ceremonies, etc.
- Some DFC initiatives have been evaluated, however barriers include: resources (including the capacity of those at grassroots level to collect

monitoring data) and the methodological challenges related to measuring culture and system change.

- Key factors promoting the sustainability of DFCs include: a broad and strong alliance, structures to build the capacity of groups of people with dementia, and the 'mainstreaming' of initiatives into day-to-day business by emphasising legal rights and benefits to businesses and by embedding them into wider strategies and training programmes.

Proposed model and indicators
Based on the evidence reviewed, the team proposes a model which summarises the structure, processes, values, and types of activities of an effective DFC. This is presented in the diagram overleaf.

The evidence gathered for this review suggests that sustainability is best promoted where DFCs:

- Are based on a broad alliance, which includes people with dementia and in which responsibility and leadership is shared;
- Activities are mainstreamed into local plans, strategies and training initiatives;
- There is a long term commitment to this agenda, including political commitment; not a belief that a DFC is something which can be quickly achieved;
- Evidence is gathered to build a 'business case' for activities;
- Opportunities to learn and share experiences from other projects and nations are maximised; and
- The focus is on bringing the Dementia Friendliness agenda in line with the disability rights agenda.

A framework for the development of indicators is proposed, which sets out broad measures for inputs (under the headings of Networks and Resources) and outputs, outcomes and impact (under the headings of People and Place).

Benefits
Perceived benefits and outcomes of an effective DFC, drawn from the analysis of this report, have been extracted and classified as qualitative or quantitative. These benefits will be tracked and monitored in the pilot stage of the EU Joint Action Workpackage.

Recommendations
Based on the evidence reviewed for this project and in relation to the development of the pilot stage of the EU Joint Action Workpackage, the research team recommends:

- That the pilots follow, test and refine the model proposed;

- That the pilots ensure the input of people with dementia throughout and maintain their focus on the value base outlined within the model: these should form key selection criteria and projects should be asked regularly to demonstrate how they are meeting these criteria during the funding period;
- For the tested toolkit to be most amenable to diffusion and successful adoption throughout EU28, the pilot sites should cover both large and small populations, be set in a mix of urban and rural settings and be spread across a number of countries with different cultures, languages, economic circumstances and health and social care systems. The pilot sites should also constitute a mix of fledgling and more mature dementia friendly communities. This should help to overcome some of the limitations of this review, in the sense that evidence has been drawn from more mature DFCs, typically from Northern European Countries. It is understood that the current proposed selection of pilots looks to address this by exploring pilot sites in Greece (with a more rural focus), Bulgaria (a fledgling DFC) and Italy.
- That projects are required at the start of the funding period to develop an evaluation framework which sets out a Theory of Change for their initiative (which problems they plan to tackle and how) and identifies relevant indicators and a plan for measuring these.
- That Work Package 7 members work to synergise the model proposed in this report with the Dementia Friendly Initiatives framework and toolkit being developed by the WHO, to arrive at a toolkit that maximises evidence drawn from both, and gives a consistent picture of best practice. Employing this synergised toolkit would accelerate progress and timescales as expertise on specifications and testing, developed through the WHO activity, could be capitalised upon in the pilot stage.

The review identified a significant number of evaluations which are in process, suggesting that a follow-up evidence review might usefully be conducted in approximately two years' time.

There is a separate technical report of the methodology and sources for the review. The model for an effective DFC is provided in the diagram below:

DFC Model[1]

Based on proposed core features/essential participants in a 'good' DFC, tested in alignment with other existing models (such as the Alzheimer's Society England's recognition process (Alzheimer's Society and DAA 2015), the British Institute of Standards

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1. INTRODUCTION

1.2 Background to this commission

The overall aim of the European Union's Joint Action on Dementia (EU JA) is to promote the implementation in Member States of coordinated actions to improve the situation of people with dementia and their carers.

This report forms part of Work Package 7 (WP7), which has an overarching objective to provide European Union (EU) Member States with clear, evidence-based and tested information with recommendations on how to effect change and improvement, to support people with dementia to live at home through the development of Dementia Friendly Communities (DFCs). This work package is being led by the English Department of Health.

Following an open competitive tender process, the English Department of Health commissioned Imogen Blood & Associates, in partnership with Innovations in Dementia, to produce a written evidence review report, drawing on both primary and secondary data sources. The overall purpose of identifying and testing evidence-based practice towards the development, promotion and sustainability of DFCs, is achieved in the collection and collation of a broad range of evidence from best practice globally. This work will inform the future development of a toolkit and metrics and will also inform the design, identification and agreement of pilot sites in the next phases of the work package.

This report aims to:

- Identify evidence-based examples of best practice in key aspects of promoting, nurturing and sustaining DFCs;

- To propose a robust definition or definitions of DFCs which can be applied to, and makes sense across, all EU Member States; setting out why they are desirable and where and how well they are operating in practice;

- To identify, from the evidence, what a 'good' or 'effective' DFC should look like in the EU, including the key components and characteristics, essential participants and enablers and barriers; and

- To propose, from the evidence, a set of indicators which might be used to test the success of the forthcoming pilots.

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1.3 The evidence on which this report is based

This evidence review was conducted over a three-month period from September to December 2016. Amendments were made following peer review during summer 2017.

The report is based on:

- A review of 82 reports and articles identified through a systematic search for international published and 'grey' literature;
- Three group discussions with people with dementia, including the European Working Group of People with Dementia (emerging findings were presented at their meeting in Brussels, in December 2016) and two groups within the DEEP network[2] in England;
- 20 interviews with 25 participants were conducted with people involved in DFCs across Europe, including two visits to projects in the UK to observe and meet local residents. Interviewees came from 10 countries across the EU (listed in Appendix 2); many more countries were invited but were not in a position to take part for variety of reasons;
- An online survey was sent out to EU dementia leads and contacts, asking them to distribute to those with a professional and/or personal interest. 57 responses were received from the UK, Norway, Republic of Ireland, the Netherlands, France, Poland, Spain and Italy.

Further detail about the methodology is included in a separate technical report.

This research team consisted of: Imogen Blood, Steve Milton (Innovations in Dementia), Ian Copeman, Shelly Dulson, Shani Blumenfeld and Jenny Pannell. Further information about the team members and their role in this project is included in Appendix 2.

The research team would like to acknowledge the support and input of the English Department of Health, the Alzheimer's Society (England), Alzheimer's Europe, the European Working Group of People with Dementia, Face It Together (FIT) in Bradford, Redditch and Bromsgrove Friends Together, those who reviewed the finished report, Geoff Huggins, Gillian Barclay (Scottish Government), Frank Hagelstein (Ministry of Health, Welfare and Sport, Netherlands) and all those who contributed to this report through interviews, survey responses or email clarifications. Particularly, the research team would like to acknowledge the support and input of the Workpackage 7 partners from Greece (National and Kapodistrian University of Athens) and Bulgaria (Bulgarian Society of Dementia) in developing and advising on the content of this report, specifically the input of Antonios Politis and Shima Mehrabian on the evaluation advisory group and as professional interviewees.

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[2] The Dementia Engagement & Empowerment Project (DEEP) brings together groups of people with dementia from across the UK. DEEP supports these groups to try to change services and policies that affect the lives of people with dementia

Additionally, the research team would like to acknowledge the input of Workpackage 3 of the EU Joint action – Vicky Serra-Sutton, Maria-Dolors Estrada, Marta Arcas (AQuAS) - for peer-reviewing the report, evaluating its methodological quality, and ensuring its alignment with an acceptable quality threshold.

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1.4 The structure of this report

The core of this report is structured around the 'Four Cornerstones' model proposed by Innovations in Dementia and shown below. The model identifies four different aspects of DFCs: 'People', 'Place', 'Networks' and 'Resources', with the voices and experiences of people living with dementia running though the centre of each. This model has been used successfully as an analytical tool and report structure in a number of evaluations of DFCs in the UK. This includes the Joseph Rowntree Foundation evaluations of work in York (2015a), Bradford (2015b) and Northern Ireland (Seydak et al., 2015), and Evaluation Support Scotland's evaluation of Dementia Friendly Edinburgh (Henderson, 2015).

Four Cornerstones Model:

Place
How do public spaces, housing, transport and written information affect people with dementia?

People
How well are people with dementia supported by those around them?

What can be done to raise awareness?

How are people with dementia and carers involved and heard?

Resources
How can resources be targeted towards a community-based approach?

How are community resources supported and encouraged to be accessible?

Networks
How well do distinct community sectors work together to support people with dementia e.g., local Dementia Alliance?

Are there other ways to network?

Source: Innovations in Dementia (2012) Developing dementia-friendly communities

The introductory chapter considers definitions and a concluding chapter presents a model which summarises what a 'good' or 'effective' DFC should look like in the EU and proposes a set of indicators against which success might be tested. As in the model above, the views of people with dementia and their supporters runs throughout this report and each of the four cornerstone sections considers how they can and should be involved. A separate easy read summary of the report has been produced and shared with participants.

The report includes examples from as many countries outside of the UK as possible, though the UK is significantly over-represented here. This reflects the fact that work on DFCs is

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non-existent, or in its infancy in many member states (Alzheimer's Europe, 2015) and also that the focus of this review has been on *evidence-based* examples. The evidence base for DFCs is at an early stage of development generally and seems to be even less well-developed across some parts of Europe. Furthermore, the time, resource and language constraints of this project have inevitably skewed the team towards reports and articles in the English language. Respondents from a number of countries explained that they were just starting work – or evaluations of work – on DFCs, so this evidence base should develop in the coming months and years. In the meantime, there is an emerging evidence base from outside of the EU, and the team was asked by the English Department of Health to look briefly at this. The review therefore included examples from Australia, Canada, Japan and the USA, where these are evidence-based and no comparable examples could be identified within Europe.

Where it has not been possible to find examples of practice which have been evaluated, the team has sought to find examples which:
- Mention a planned evaluation or at least some published/ publicly available information;
- Demonstrates values and approaches which the findings of the evidence (including both primary data from people with dementia and existing published literature) support; and
- Are drawn from as much of a range of EU countries as possible (though again the team recognises there is a bias towards UK examples).

2. WHAT IS A DEMENTIA FRIENDLY COMMUNITY?

2.1 Why try to make our communities more 'Dementia friendly'?

Dementia has massive impact:

Dementia has a huge impact on those with a diagnosis, those close to them, and society more generally (Innovations in Dementia / LGA, 2015):

- In 2008, Alzheimer's Europe (Wimo et al, 2008) estimated the cost of 'dementia disorders' to the 27 countries of the European Union to be €160 billion, of which 56% were costs of informal care.
- People fear dementia more than any other disease. A survey of people in the UK found that 39% of over 55s worry about getting Alzheimer's the most out of a number of serious health conditions, compared to 25% who worry most about cancer (English Department of Health 2015);

People with dementia want to live everyday lives:

Research and practice with people with dementia reveals a strong desire to live well, to continue with 'the stuff of life' and to stay connected to their interests, social networks and communities (e.g. O'Rourke et al, 2015; Von Kutzleben et al, 2012). Yet research conducted in the UK for the Alzheimer's Society (Alzheimer's Society 2013) suggests that many people with dementia withdraw from their communities.

If people with dementia and their supporters can be included more effectively in the mainstream lives of their communities, there is a strong argument that their quality of life can be improved, the stigma and fear surrounding the condition can be lessened, and – ultimately – the costs of care (especially of formal, institutional care) may be reduced.

Improving services and neighbourhoods for people with dementia improves them for everyone:

Many of the changes proposed by DFCs make services and neighbourhoods better for all of us. Everyone can benefit from clearer information, better signage and more logical layouts, and from better customer service.

3. DEFINITIONS: CHALLENGES AND CONTESTS

There is, at present, no single agreed model across Europe for what a 'Dementia Friendly Community' is (Williamson, 2016). Definitions of 'community' and 'Dementia Friendly' vary significantly, as do the preferred terms to describe this collection of medical conditions. For example, in France and Finland, 'dementia' is not an acceptable term; some countries prefer to use 'Alzheimer's Disease'; others feel this is too medical, and in any case is only one of many causes of dementia. Even in the English language, several terms are used almost inter-changeably with 'Dementia Friendly Communities', such as 'dementia supportive communities', 'dementia capable communities' or 'memory-friendly communities'. For the purposes of this report, the term 'Dementia Friendly Communities (DFCs)' is used.

Williamson's (2016) recent review of DFCs across Europe for the European Foundations' Initiative on Dementia distinguished definitions which focus on *process* (describing the types of activities which might be undertaken) from those which focus on *outcomes* (usually from the perspectives of people with dementia and/or their carers). Some outcome-based definitions are broad and linked to values (such as empowerment, inclusion or quality of life); others are more practical (such as feeling safe or being able to access local facilities).

The literature on DFCs and the interviews conducted for this review highlight a number of criticisms of the term. Firstly, 'dementia' is not a single condition:

> Dementia is effectively an umbrella term for a number of conditions [...] 'dementia' is inadequate to describe this heterogeneity: people can have very different access

needs arising from these different conditions. So it's a very complex and variable condition, plus the fact that there is profound co-morbidity – there are very high rates of other physical, learning disabilities / mental health problems alongside dementia.

<div align="right">(Author and medic, England)</div>

Some of those interviewed felt that placing such an emphasis on a diagnosed condition risked further stigmatising and separating people with dementia: they pointed out that a better aim would be to create communities which are more 'friendly' and accessible to *all*. Others were concerned that, especially in some countries within the European Union, rates of diagnosis of dementia are very low. Although poor diagnostic practice is undoubtedly still a huge issue, in relation to DFCs, it seems that practical steps to remove barriers which benefit those with a diagnosis, will also benefit those without, providing they do not depend on people knowing, proving and identifying themselves as having dementia.

Secondly, there has been considerable critique of the term 'friendly' in this context (e.g. Swaffer,2014; Rahman,2015):

> 'Friendly' is the wrong term here – it is patronising and disempowering. The last thing you want if you have dementia is to be patted on the shoulder'

<div align="right">(Person with dementia).</div>

There is increasing literature and a developing movement in relation to the citizenship of people with dementia (Bartlett, 2016; Nedlund and Nordh, 2016; Hare 2016). Although the word 'friendly' is used throughout this report, the evidence gathered for this review, including the views of people with dementia, demonstrates the importance of this agenda being about rights, equality and inclusion for people with dementia, not the (perhaps more optional) 'friendliness'.

Thirdly, there is a tension in relation to what is meant by 'community' and, crucially, who decides. As one interviewee explained:

> 'Community in this context has often tended to be defined (often by the statutory sector) in terms of 'administrative areas' (e.g. local authority areas), but we know from working with people with dementia that community often means different things including clubs, personal networks, local neighbourhoods, none of which may relate at all to administrative definitions of communities'.

3.1 Proposing a Europe-wide definition

The online survey conducted for this review contained the open question 'What does the term "Dementia Friendly Community" mean to you?'. Although there were many different responses to this question, all contained some or all of the following notions:

- Acceptance / understanding / lack of stigma;
- Inclusion / community-led responsibility;
- Feeling safe and secure; and
- Being respected.

Similar findings emerged from the interviews: acceptance, lack of stigma and inclusion in 'normal' or mainstream life were recurring themes. Many people spoke of the importance of taking an asset- or strengths-based approach, which recognises and builds on the existing resources both of communities and of people with dementia. Others emphasised how important it is to apply a social model of disability, which focuses on how physical environments, processes and attitudes disable people with dementia, rather than a medical model, which focuses on how an individual's symptoms and impairments disable them:

> The difficulties which dementia may bring are taken as something that society has to solve rather than locating a problem with the individual living with dementia.

> (DFC Coordinator, England, survey)

Survey respondents were also asked for their comments on four existing published definitions (these are included in the Technical Report). There was evidence of a tension between process and outcome definitions: some people wanted descriptions of how to achieve the over-arching objectives, others felt these were too specific or limiting. The feedback around language was more consistent: this needs to be accessible and succinct. People welcomed positive language in relation to people with dementia, but felt some terms were unrealistic – a number of people questioned 'high aspirations', 'high quality of life' or 'continuing to belong' (where some might not have felt they belonged in the first place).

The following definition was developed by the research team, having analysed all these responses. The authors acknowledge that there will always be differences of opinion, language, culture and approach, however, the proposed definition aims to incorporate the key points raised by survey respondents and interviewees, including people with dementia and caregivers. The first sentence sets out the overarching outcome; the second describes the process in broad terms.

> **In a 'Dementia Friendly Community', people with dementia are included and respected. Citizens, organisations and businesses work together to remove the barriers which stop people with dementia and their supporters from participating in community life.**

This definition has a number of strengths, which resonate with the key themes from this review:

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- It uses a social model of disability, in which the onus is on society to remove barriers;
- It focuses on inclusion within community life and assumes that people with dementia have a contribution to make;
- It does not attempt to define the size or nature of 'a community';
- It avoids specific descriptions of the type of barriers that need to be removed and how, since this needs to be determined locally, with people with dementia;
- However, it makes it clear that the main mechanism for achieving this is the alliance between citizens, organisations and businesses; and
- It puts people with dementia at the heart of the vision, whilst also making separate reference to their 'supporters' (who may be family, friends or neighbours and who may or may not define themselves as 'carers') – since we recognise that they are often excluded from community life too (Carers UK, 2016).

There are, nevertheless a number of significant caveats to this definition:

- DFCs need to be seen as a path and a process – rather than a state. A recurring theme from the interviews was that 'people need to realise it is a long journey' and, as a result of this some explained that 'we always say we are working towards being a DFC'. Another interviewee highlighted the fact that DFCs should be learning communities or structures, which explore, experiment, test and revise different approaches.
- The activities and detailed structures of DFCs, needs to be defined locally – at least in terms of their activities and structures - not at a national or European level; though, as Williamson (2016) argued, there are principles here which can and perhaps should be universal;
- Most crucially, DFCs need to be defined (both in terms of their priorities and the impact of their activities) by people with dementia and carers (not 'top-down');
- DFCs mean different things to different people; some ambiguity and contest is, perhaps, inevitable given different vested interests and personal experiences.

Although the exact focus for work in any DFC needs to be determined locally, the British Standards Institute (2015) in its Code of Practice for the recognition of DFCs in England sets out eight 'areas for action'. These can provide a useful tool for thinking about the breadth and different types of activities which might be undertaken in an area:
- arts, culture, leisure and recreation;
- businesses and shops;
- children, young people and students;
- community, voluntary, faith groups and organizations;
- fire and police;
- health and social care;
- housing; and
- Transport.

4. PEOPLE

A clear message emerged from both the interviews and group discussions: the attitudes and behaviour of people are more critical to the creation of a DFC than the physical environment. The role of people in creating community has been underlined by recent research which found that social relationships were the single largest contributing factor to wellbeing (Clark et al., 2016).

As one interviewee commented:

> How we see dementia and how we treat those who live with dementia both have a profound impact on how dementia affects those living with it and how it develops. A better life with dementia starts in our minds.
>
> (German professional involved in developing DFCs)

Tackling stigma and fear, breaking the taboo which often surrounds dementia, and giving people in customer-facing roles the empathy, skills and confidence to respond positively and supportively have been the primary goals of much of the Dementia Friendly activity across Europe to date.

In Norway, for example, Nasjonalforeningen for folkehelsen (National Association for Public Health) explained:

> The primary focus here has very much been around arranging awareness sessions for those working in shops, cafes, etc. We think that spreading more awareness and knowledge about dementia amongst the general public is key to making communities more inclusive. We have focused less on the physical environment to date, but we still think this is important and this will be our next step.

However, if some of the concerns voiced in relation to the DFC movement and concept in the introductory section are to be tackled, the content and messaging of this awareness raising is absolutely critical. As one interviewee from England warned:

> Be open to involving people with dementia in everything you do – without that, you see people make some terrible mistakes […] it ends up being about people with dementia being done to, patted on the shoulder, etc. when it should be about collaboration.

This was summed up by a person with dementia attending one of the group discussions:

> If you have got it [dementia] you understand it, where in the sense if you understand the difficulties and problems so that you are much more capable of suggesting to somebody else what might have worked for you or what we are hoping will work for all of us.

Given this, the first section of this chapter presents some of the experiences of people with dementia consulted as part of this review in relation to their encounters with others in everyday settings.

4.1 People's experiences of everyday social interaction

The people with dementia who contributed to this review described various forms of discrimination which they experience in their daily lives:

Being dismissed:

'I think not being taken seriously is the thing that aggravates me. You know when I say something perfectly sensible and people disregard it because it is me that said it. I find that very frustrating.'

Being avoided:

'I was embarrassing some other people in this one particular place, one of our favourite places [where my wife and I go dancing] because they don't know whether to come and speak to me or – she says, "He's alright, he just wants to say hello to you"'.

Being stereotyped:

'I have a feeling that people think of people with dementia as somebody who goes around without any clothes on or people who do wild and wonderful things. Do you know what I am saying? Because they think you are demented.'

Being labelled:

'I realise now I have been labelled - I have an aunt who had it [dementia] […] as children we thought she was crackers […] But, looking back on it, I think "Oh, am I going to turn out like her?" […] you know […] but we didn't know what it was; it was just auntie […] now it seems to be a big thing, it has got labels.'

Your condition being minimised, doubted or mocked:

'I mean people have said to me, "Oh, don't worry about it, it is just getting old".'

'I have had a lot of problems with people doubting I've got dementia'.

'Some people mock it a bit – they keep going on about forgetting stuff'.

People described some of the challenges they face when interacting with others as a result of their condition. Although many of these relate to memory loss; interestingly,

communication emerges as the primary challenge for many, reinforcing the primacy of relationships in the creation of community.

Challenges with communication:

'I know what I am talking about but I can't quite work the words out sometimes. Then I just stop it then. I know what I am doing, but it doesn't sound right you know'.

'The speed at which people talk and dementia don't go together nowadays. If people can start at a big fast rate, you can't tell them, it just doesn't go in, it goes over the top and if you slow down to talk to them they get cross with you because you are delaying somebody else.

Challenges with memory loss:

'Forgetting names is my biggest problem, I know it is a silly thing, but it is very embarrassing'.

This point again confirms the importance of relationships.

'I have come across the road this morning, stood waiting for the bus and I stood there thinking, "Where's my wallet?" I had to go back because you worry about things, and the wallet is upstairs at the side of the bed because I hadn't picked it up, that's what really affects me, I can't remember things like that […]'

Fear of experiencing discrimination:

Fear of experiencing discrimination – or just ending up feeling awkward – mean that many people do not want to tell others, especially strangers, about their dementia:

'You don't want anybody to know, that you are slightly different. You want people to just accept you as you are. But then something goes wrong and people look at you as if to say, "Why did you do that stupid thing?"'

These fears and negative experiences can have a huge impact on the confidence of people with dementia, who often prefer to withdraw than risk rejection or humiliation:

'I often pull back from conversations with people because I'm worried about forgetting the words or it just being difficult'.

The people with dementia who contributed to this review made lots of practical suggestions about how various members of the community can support them effectively:

Providing extra practical help, with discretion:

'It's often about really simple things – like if I go into a shop, I can't count out my money so I might need help at the till – or I might go in and need help to find where something is – but

I also might not be able to remember the word for it, so I need to be able to describe it to someone who can then take me to it (discreetly and without treating me like I'm mad or stupid)'.

Not singling you out – or needing to know why you are having a problem, just providing everyone with good customer service:

'It is very difficult to know who has got dementia I mean the ladies and gentlemen who do the checkouts in the supermarkets they can't spot us because we don't have a flag on our heads, they don't know'.

'But they should be aware of anyone struggling that might need a bit of extra support'.

'It is about good customer service then, isn't it really, and what everybody should be expecting'.

'Everybody should have good service'.

These last two comments are key as they both make the point that a DFC will be better for everyone: as several interviewees suggested, it is as much about a 'friendly community'. Members of the European Working Group of People with Dementia also voiced concerns that there is a risk of DFC initiatives becoming quite divisive: for example, it is important that people with dementia do not have to identify themselves by going and standing in the 'Dementia Friendly' queue at the supermarket. People want to be able to integrate as much as possible and 'feel normal' and this also means that people who have not been diagnosed can benefit as well as those who have.

Not assuming you can use automated processes:

'There was a big queue […] the woman at the bank […] said "You can use the machine", but I can't. Well she didn't know, but you know I said, "No, I can only do it this way"'.

[Another member of the group] 'It would have been better if she said, "Are you able to use?" rather than […]'

Slowing down / checking whether people can understand you:

'I have been trying to get some car insurance and the lady who I spoke to [on the phone] she must have read this script; it was so fast. It was "Blah blah blah blah…".'

Neighbours offering practical support (in a non-patronising manner):

'If you tell them what you have got […] I get neighbours coming saying, "I am going up the town do you want to come up with me on the bus?" […] things like that'.

Seeing the person behind the label:

'It's just a name; I am still me'

4.2 Key findings from wider research evidence with people with dementia

The direct evidence gathered from people with dementia was supplemented with a brief review of existing research on the key drivers of quality of life for people with dementia and their carers that relate to community life.

In England, Williamson (2010) surveyed people with dementia (including some people with more severe symptoms, living in care homes) to identify their top ten quality of life indicators. 'Relationships' again emerged at the top of the list; with 'environment' a close second.

O'Rourke, et al (2015) searched for all the qualitative studies that had asked people with dementia what influences their quality of life. She and her team found that relationships and feeling connected to others were the most important factors. Reciprocity (being able to help as well as be helped), respect and kindness were the cornerstones of positive interactions. They concluded that:

> 'Relationships supported people with dementia in becoming purposeful through goal achievement or participation in desired activities' (p.30).

Von Kutzleben, et al (2012) had conducted a similar exercise a few years earlier. Similar themes emerged: the needs which were most commonly expressed by people with dementia were for social inclusion and a positive sense of self. Yet, as it would for anyone, 'the way they are treated by others influences their self-image' (p.385). A recurring theme was that:

> 'Despite the impact of the disease, most people diagnosed with dementia try to maintain normality, and continue their lives in the best possible way' (p.386).

This desire to continue with 'a normal life' was a recurring theme in our engagement with people with dementia and in other studies. For example, Norway's Nasjonalforeningen for folkehelsen have conducted a survey of a hundred people with dementia and their carers:

> The main message from this was that people with dementia want to live as a normal a life as possible and that, in order to do this, they need to be met with good attitudes and, where necessary, help. This was no great surprise, but it confirmed our approach to raising awareness, supporting people to communicate more effectively and understanding how and why help might be needed.

(Interview with representatives of Nasjonalforeningen for folkehelsen)

4.3 Family care-givers' perspectives

Unpaid carers[3] play a huge role in supporting people with dementia across Europe. Estimates of the proportion of people with dementia living with family in the community gathered by Alzheimer's Europe in (2013) show huge diversity here: in Finland around 20-30% of people with dementia (including those not yet formally diagnosed) were estimated to be living at home with family or friends, but this rose to 50% in Greece, 80% in Italy and 98% in Bulgaria.

Research in the UK also shows the increasing number of older people caring for someone with dementia (Newbronner et al., 2013). Older carers typically care for a partner or parent in their 80s and 90s, and may be unable to continue in paid or voluntary work: there is a risk here of both the person with dementia and their carer(s) becoming isolated and unable to access their local community. However, many working-age people are also carers (sometimes at a distance) and may be supporting their other parent in their role as primary carer.

The report by the Carers Trust (Newbronner et al., 2013) draws on research across the UK and includes studies of minority groups. Every study emphasises the value carers placed on the support provided by informal networks and their local communities, including:

- In remote rural Scotland where a supportive local community was invaluable (Blackstock et al, 2006);
- For lesbian carers, who found support from friends more helpful than government or voluntary sector services (Price, 2011);
- For carers whose friends and neighbours helped to monitor their relative, for example when they wandered and got lost (Egdell et al, 2010); and
- For carers of people with Down's syndrome and dementia, who also talked about the benefits of knowing other carers (McLaughlin and Jones, 2011).

Bennett (2015) also found that older spousal carers may value the support of strong friendships (often in their local communities) even more than strong family relationships (Bennet, 2015).

Data from a 2016 UK-wide survey of over 5,600 carers (caring for people all ages and all disabilities) found that three-quarters of carers believe their community does not understand or value their caring role; and this lack of understanding can have a negative impact on their health, wellbeing, relationships, and finances (Carers UK, 2016).

In a group discussion conducted for this review, a partner-carer said:

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[3] We are use 'carers', 'care-givers' and 'supporters' interchangeably throughout this report to refer to (usually unpaid) family members or friends, in contrast to 'care staff' (e.g. home-care assistants).

Imogen Blood & Associates & Innovations in Dementia

As a carer I am also part of the same community. I also need to remain engaged in my activities and continue to feel that I can contribute and offer value to my community. As a carer, life is different - it's my choice, so it's fine, but the community needs to understand that [my partner] and I we come as a team, this is part of the education needed.

(Partner of a EWGPWD member)

There was a high degree of consistency between the research findings reviewed and the views of the people with dementia and carers we spoke to during this review. The following key messages of particular significance to the development of DFCs, emerge from the evidence:

- Relationships and interactions with people are of primary importance in driving the quality of life of people with dementia;
- The 'environment' is the next most important factor;
- People with dementia are particularly concerned to maintain 'normality' as much as they can. They would like to continue going to the same places, maintain relationships with the same friends, be part of their communities and still 'be me'.
- People with dementia want to continue to make a contribution: to help others as well as to be helped themselves;
- Stigma, discrimination, loss of status and the fear of social rejection are the main barriers to social inclusion and therefore to quality of life.

4.4 Current activities to change people's attitudes and behaviours towards people with dementia

Awareness raising and training

Almost all of the DFC initiatives reviewed for this project contain an element of awareness raising, typically in the form of delivering group training sessions and/or distributing materials, such as videos and guides. The National Centre for Social Research (Reid et al., 2015) surveyed 1500 members of the general public in Scotland on their attitudes to dementia. Their findings suggest a link between knowledge and helping behaviour: those who said they knew 'a great deal' or 'quite a lot' about dementia were more likely to say they would be willing to help a neighbour with dementia. This suggests that awareness raising may improve 'helpfulness', though there are a number of health warnings here. Firstly, there seems to be little evidence regarding how likely people are to act on these intentions and exactly *how* they will act.

One interviewee expressed concerns that a little knowledge can be quite dangerous, leading to people making assumptions, or inappropriate offers of help:

Every person with dementia is different and I worry that, if you have had two hours of training, you will meet every person with dementia through this lens […] You have to know what you don't know.

The content and messaging of awareness-raising sessions and materials are therefore absolutely critical and, again, the main success criteria seems to be the involvement of people with dementia in design and/or delivery. Between 2014 and 2016, over a thousand community members living in the Kiama area of Australia participated in awareness-raising activities. The project's comprehensive evaluation concluded that:

'Importantly, these events involved both 'education' and 'contact' with people with dementia who were involved in the development and delivery of all educational activities' (Phillipson et al., 2016, p.6).

As one interviewee explained:

I think the message about dementia is so much more powerful when it is given by people with dementia [...] as soon as they start talking about their own story that's when people are engaged.

(Professional involved in a Dementia Alliance)

Content of training sessions

In the DEED project in Northern Ireland, the basic awareness raising sessions (which have been positively evaluated by Seydak et al, 2015) lasted around two hours and covered:

- Basic understanding of dementia;
- Practical techniques for communicating with people with dementia; and
- Information on small adjustments to the physical environment to improve access.

The representatives of Norway's Nasjonalforeningen for folkehelsen explained that the following messages are clear in their awareness-raising materials:

- There are many different cognitive impairments;
- Our focus is less on the medical symptoms, and more on making practical adjustments and communication skills;
- It is about creating a more friendly society for everyone, giving the customer a bit of extra attention; and
- Dementia is not an inevitable part of the normal ageing process.

Their PowerPoint presentation includes an embedded film in which a woman with dementia talks about her experiences.

What does the evidence tell us about how best to engage people in awareness raising activities?

- Hearing the direct experiences of people with dementia and their carers is really powerful: it can help people to empathise and engage (Phillipson et al., 2016)
- Targeted, bespoke, role-specific training is more effective than a standardised session, since this gives participants the opportunity to consider the practical implications for their business, workplace, etc. (Henwood, 2015);
- Taking the training out to businesses can be more effective than expecting them to free up staff time to attend a public information session. For example, in Hampshire, England (IPC, 2015) this included some training being delivered over the counter in shops and reception areas, during quieter periods.

What evidence is there of outcomes?

Training and awareness raising sessions are frequently evaluated using pre- and post-session participant questionnaires. For example, in Seydak's (2015) evaluation of the DEED project in Northern Ireland, pre- and post-session evaluation forms showed an increase of 47 percentage points in the percentage of participants who described their level of confidence and skills in communicating with and supporting people with dementia as 'Good' or 'Very Good' following the session. Participants were also asked to list their intended actions (linked to People, Place, Networks and Resources) following the session. However, the review did not find any published evidence regarding the actual behaviours of participants following awareness-raising sessions.

Appendix 1 (1.1 – 1.5) lists practice examples of:

- Awareness raising and training sessions;
- Media;
- Intergenerational work;
- Enabling people with dementia to make a contribution; and
- Providing support to people with dementia to access community life.

4.5 Summary of key points and recommendations from this chapter

This section has demonstrated that the awareness and acceptance of other people is a key enabler of a DFC. The review has identified a number of barriers which people with dementia and their supporters encounter in their social relationships and day-to-day encounters with other people.

DFCs may include various activities aimed at changing people's attitudes and behaviours towards people with dementia, including:

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- Awareness raising – through awareness raising or more formal training sessions, use of media, and intergenerational work;
- Opportunities for people with dementia and their carers to make a contribution, through voluntary work, including but not limited to providing peer support;
- One-to-one support to people with dementia to help them to access mainstream community life.

Based on the evidence reviewed, the authors recommend that these activities:
- Involve people with lived experience in developing and delivering awareness raising activities and products;
- Focus on practical adjustments and communication skills;
- Are made specific to the roles of people working in different settings, wherever possible; and
- Create and emphasise the importance of opportunities for people with dementia to participate in and contribute to mainstream community life (i.e. not just in separate, specialist activities).

5. PLACE

5.1 Reclaiming the rights of people with dementia to access public spaces

In 2003, when Mitchell et al reviewed the literature and guidance on dementia and design of the physical environment, it seems significant that they found: 'None of the guides gives advice on the design of the outdoor environment beyond the boundaries of dementia care homes.' (p.618). Stirling University's book on Designing Outdoor Spaces for People with Dementia (Pollark and Marshall, 2012) contains one chapter on public spaces; the remainder looks at the gardens of care facilities.

The assumption seems to be that the public realm is not (or has not been) relevant to people with dementia. One of the participants in our group discussion told us that her friend's son had said to her as soon as she was diagnosed: 'If you've got dementia, you should go in a home'.

In some European countries there has been a well-established tradition of people with dementia living in care homes, hospitals and other institutional settings. In these countries, the DFC movement has the potential to assert the citizenship of people with dementia; to reclaim their rights within the public realm.

In European countries where a much higher proportion of people with dementia live in ordinary homes – often with relatives – less is known about the extent to which they are integrated within the life of the community. However, findings from the individual and group interviews with people from Bulgaria, Italy, Portugal and Greece suggest that people with

dementia are often 'hidden away', with this especially being the case in the islands or more rural areas.

An evidence based practice example of enabling people with dementia to reclaim public space can be found in Appendix 1 (1.6).

5.2 Place, community and people with dementia: messages from research evidence

There is an emerging evidence base which demonstrates the importance of place in enabling the resilience and citizenship of people with dementia. Clarke & Bailey's (2016) study of the everyday experiences of living with dementia within rural and semi-urban communities in North East England found that familiarity with place and people can be supportive. In this study, being in places that people knew well gave them continuity and stability, and attachments to place played a key role in people's stories about 'feeling on the inside'.

Allen et al.'s 2015 study of the English town of Hebden Bridge suggests that pride in and identification with place can drive mutual support and friendliness in communities. This idea that 'we do things differently here' can be a key driver within DFC initiatives, especially where a village, town or city is the focal point. One person interviewed for this review explained:

'We've been in Up North and BBC Breakfast on the television […] so I think there is a big pride factor […] that it's Rothwell' (Coordinator, Dementia Friendly Rothwell).

Places are not simply a physical location or material setting: 'they are profoundly relational' (Phillips et al., 2015); we cannot fully separate the relationships we have with a place and the relationships we have with the people in that place. For people with dementia, things and places can spark memories and conversations, which in turn can build relationships. (Phillips et al., 2015)

Strong social support already exists between neighbours in some communities and this can be a key component of a DFC. Wiersma & Denton (2013) have, for instance, studied the 'safety net' which communities in rural northern Ontario, Canada, can offer neighbours who develop dementia. This 'culture of care' seems to be driven by people's length of residence and also by the remoteness and weather conditions of the place: people offer to help dig out snow and fetch groceries for their more vulnerable neighbours, including those with dementia.

However, there are important health warnings here: stigma can be very strong in some rural communities. Some of the people with dementia in Clarke & Bailey's (2016) study found the familiarity of their close-knit communities challenging: they chose to withdraw socially because of fear of embarrassment. Wiersma & Denton (2013) also highlight the limits to the support offered to people with dementia, especially those who were not so well-connected

before they developed the condition and, crucially, they did not ask people with dementia how *they* experienced the support.

5.3 What are the barriers and enablers for people with dementia in relation to place?

The International University of Japan (2014) surveyed 300 people who have dementia. Around two-thirds of those responding said they went out to shop, eat, see friends and use public transport much less than they did before they were affected by dementia. The main reasons for this included:

- Getting lost at train stations / difficulty finding the right bus stop (51% cited this);
- Difficulty using ticket machines, automated gates, etc. (50% cited this);
- Difficulty using cash machines (44% cited this); and
- Difficulty using devices, such as phones, email, internet (44% cited this).

The people with dementia who informed this review described these barriers and others in relation to the accessibility of the physical environment and of information and systems:

Everyday automation and technology: 'Accessing a cash point - that is a no-no. I went to the swimming baths while my wife went shopping and I couldn't use the vending machine'.

Flooring: black, very shiny or 'busy' patterns can be disorienting and off-putting.

Signage: 'I will give you an instance, coming out of these toilets, I didn't know whether to turn right or left. There is no sign saying 'back to where you came from''.

Transport: 'The buses are generally good. It helps having a bus pass so I don't have to count out my change. The only problem is, when I go to a place where I'm not as familiar with the area, I'll ask the driver to give me a shout when we get there. Sometimes they do, but often they forget. It's good in London when they have those buses with audio and visual announcements for the next stop'.

Complex layouts (especially if these are new and unfamiliar): 'I mean the old station used to be so straightforward you came through one barrier, you went up the escalators, you went down the ramp and you were in town. Now there is about 3 or 4 entrances and exits, red lounge, blue lounge, I didn't know which lounge I should be in'.

Accessible information and processes: 'I need things in straightforward language – not too much jargon, people speaking reasonably slow and not going on for too long'.

'I went to the dentist and the receptionist said, "Sign there!" I couldn't sign my name […] It wouldn't come out. And it was "Just sign on that line there." It gets worse you get worked up and you can't do it'.

5.4 Care-givers' perspectives

Although some people with dementia are able to get out and about independently in some settings, family and professional care-givers often play a key enabling role. In addition to the primary data collected from family care-givers in the group discussion with the European Working Group of People with Dementia and the online survey, the team briefly reviewed recent published research into the experiences of family care-givers.

Employers for Carers (2014) surveyed employees who were caring for someone with dementia. Nearly half (49%) were supporting their relative to access leisure facilities, and over a third (38%) gave physical help with walking / getting up and down stairs. When asked about the barriers that they and their relatives faced in their local community, around 1 in 4 (27%) asked for more accessible services (e.g. shops, banks, transport and leisure facilities etc.).

The availability and frequency of public transport, especially in rural areas (Blackstock et al., 2006; Innes et al., 2005) emerged again as limiting opportunities to engage in the local community.

Innes et al. (2015) asked care-givers in England to describe the challenges they and the person with dementia they support encounter when trying to participate in leisure activities. Public toilet provision was highlighted as a major concern. This was a particular issue where the person with dementia and their care-giver were of different gender but toilet provision was gender specific.

The fear of losing the person they are supporting has also emerged as a key theme in published qualitative research with carers. For example, carers describe very stressful experiences of getting separated from each other in busy shopping centres (Innes et al., 2015). In Blood et al (2016) a family carer explained:

> One evening recently around 9 o'clock at night, mum disappeared… She was missing for two and a half hours, so we reported it to the police. They found her three miles away - she was in a cul de sac and people looked out and saw her. They had realised what was wrong when they asked her where she was going and she said "Liverpool" [despite being many miles away], and they phoned the police.

This example highlights the key role which the Police can play in creating a DFC.

A theme which emerges from the published research on the accessibility of the physical environment for people with dementia and their supporters is the way in which barriers 'layer' up on top of each other and interact with each other to make the entire experience

problematic. For example, Innes et al (2015) found from their research with couples where one partner has dementia, that it is the combination of time pressure, complex layouts, mobility issues and noise which makes large rail interchanges problematic. Brorsson's (2016) studied the decision-making of with people with dementia in Sweden in relation to crossing roads. She found that 'it was the hazard of meeting unfolding problematic traffic situations when only one layer at a time could be kept in focus' (p.1135) which created stress, unsafe crossings, or avoidance tactics.

5.5 What works to reduce these barriers?

Involving people with dementia

As in each of the other 'cornerstones' (People – Place – Networks – Resources), the involvement of people with dementia, both in properly understanding and working to reduce barriers emerges from all the evidence as being critical. A key message throughout these activities, however, is that what makes environments better for people with dementia will also make them better for everyone.

Access audits

Bromsgrove and Redditch Friends Together (a group of people with dementia in England) were commissioned to undertake an access audit to influence the re-design of their local shopping centre. In Kiama, South Australia, a group of people with dementia conducted an access audit of the local library (Philipson, 2016).

Guidance on conducting comprehensive environmental audits has been produced in the UK by Innovations in Dementia:
http://www.innovationsindementia.org.uk/HowToDoAnAudit.pdf

Alzheimer's Australia have produced The Dementia Friendly Communities Environmental Assessment Tool:
http://www.enablingenvironments.com.au/uploads/5/0/4/5/50459523/alzheimers_enviro_assess_tool_a4-signoff.pdf

'Walking the patch'

This less formal approach might be done with one individual, accompanied by a care-giver if appropriate. This might involve walking together through a neighbourhood or journey on public transport, and asking the person how and why they take particular decisions, what they find useful and how they experience the route. For example, in Wendover, England, five members of the Dementia Action Alliance, including two members with a diagnosis of dementia and a carer who uses a mobility scooter, were separately accompanied by someone who filmed their progress as they moved around the streets of the town (Holden 2017).

Photo or video prompts

Research studies conducted with people with dementia in relation to the physical environment use photos or short films as prompts for discussion in a focus group setting (e.g. Phinney et al., 2016; Brorsson, 2016).

Annex 1 (1.7) provides practice examples relevant to public space, including:
- Making transport accessible;
- Making buildings accessible;
- Making neighbourhoods and outdoor spaces accessible;
- Making information accessible;
- Safe places to meet and mix; and
- Making clubs – in this case 'Men's Sheds' – more accessible

5.6 Summary of key points and recommendations from this chapter

Asserting the rights of people with dementia to access 'everyday' public spaces should be a core value of DFCs. People with dementia and their supporters identify a range of barriers to accessing indoor and outdoor public spaces, including: poor signage, inaccessible public transport, lack of toilets, complicated layouts, disorientating flooring and complex information and processes.

The evidence suggests that effective DFC initiatives in relation to place:
- Involve people with dementia and their carers in auditing the accessibility of places, information and systems;
- Train staff in the 'public realm' – transport workers, police, staff at public venues and customer-facing businesses;
- Work to facilitate way-finding and reduce sensory overload; and
- Create safe spaces for people with dementia and their carers to meet and mix, but also support the integration of people with dementia into mainstream clubs, organisations and services.

6. NETWORKS

The report to this point has focused on what a DFC is and the activities it might contain: its outputs. This and the following section on *Resources*, explore *how* such initiatives might be achieved: the necessary inputs. It begins with a consideration of what the evidence tells us about building networks and measuring their success.

What is it that turns a Dementia Friendly theatre, pharmacy or museum into a DFC?

Evidence from the interviews suggests that it is necessary to link up different activities by sharing information and developing a strategic approach. If coordinated action is to be taken

over a geographical area, it is essential to engage a broad network of organisations, businesses, groups and individuals, including those with lived experience of dementia.

In some of the examples of DFCs reviewed for this project, this network – typically in the form of a Dementia (Action) Alliance or similar - has been formed at the outset. This approach seems to be typical where funding has been received for a coordinator's post, though there are also examples of this happening as a result of a public meeting being organised in a local neighbourhood.

In other cases, the network seems to have grown out of the work of a single organisation to become more Dementia Friendly (as in the Austrian Community Pharmacy project, featured in the practice examples, which began to develop its local network so as to signpost and develop joint awareness raising activities).

A third model is one in which 'micro' initiatives 'bubble up' from local clubs and groups (sometimes with small amounts of funding or sometimes driven by voluntary effort alone) and are linked up strategically later on, often with leadership from local government or a voluntary sector organisation.

In an interview conducted for this review, a project officer who has been supporting the development of DFCs for the past seven years said that:

> Many of the projects that were most successful in my opinion stuck to one goal – they kept their focus on setting up an inclusive choir or a local Alzheimer's café, which doesn't sound hugely innovative but ended up connecting out much more widely across the community […] There is a tendency to want to be the first Dementia Friendly town, city or county but I think we should be encouraging people to think small, seize opportunities and right people (not just dementia professionals) to do something low key and very local or focused. Get people with dementia involved if they aren't already and those with a personal interest. The task at a higher level and over a larger area is then to try and knit these together through a shared vision.

6.1 Who needs to be involved?

> What we are saying is if people in the community understood better then there would be less stigma and also less black carpets and less stress and more patience so it is time to make everybody understand, whether it is the bank or the church, or a mosque or a school if you are picking up your grandchildren, to understand a bit more about it.   *(Person with dementia in one of the group discussions)*

The organisations, groups, businesses, and local government departments which play a role in a local community and in the lives of individuals will vary by geography, culture, personal interests and lifestyle, but may include local shops, cafes or bars, places of worship, schools, sports or social clubs, cultural and leisure venues. Then there are the services that provide the infrastructure – refuse collection, housing providers, transport, health centres and roads.

In order to build the resilience of people with dementia by supporting them to maintain the 'normality' to which most aspire (Von Kutzleben, et al, 2012), the broadest possible network of partners needs to be involved.

Respondents to the online survey were asked about the people and organisations which can enable people with dementia to take part in their community and remove the barriers which prevent them from doing so. A clear message from the responses to this question was that EVERYONE needs to be involved. Most frequently mentioned were: voluntary sector organisations, health and social care services, local authorities/ municipalities, central government, private sector businesses, emergency services, educators, the general public and people with dementia and their carers, family, friends and neighbours.

Although a broad partnership is the ideal, evidence from research and practice suggests that there is a balance to be struck between building the network and getting on with actions. One alliance chair interviewed advised that it is important to build a 'coalition of the willing', rather than work more mechanically through a list of organisations who should be present. Experience from the Alzheimer's Society Ireland (2014) programme found that some of the 'unexpected' partners proved to be the most committed.

Although the involvement of health and social care partners is important, it seems to be equally important to make sure that non-dementia specialist organisations and businesses are around the table, otherwise there is a risk that the initiative ends up focusing too much on the dementia care pathway to the expense of making other services, organisations and activities accessible. This seems to have been the case in some of the evaluations we reviewed (e.g. Henwood 2015, Chalk 2014), where the primary focus of activities has been on training doctors, nurses, and care home staff.

Practice examples of partnership structures, including Dementia Alliances in Germany and Dementia Action Alliances in England are detailed in Appendix 1 (1.8).

6.2 What are the barriers to building alliances and what works?

Recurring challenges in the DFC evaluations and our interviews with stakeholders included:

- Difficulties engaging and securing the ongoing commitment of local business and community organisations;
- Finding meaningful ways to engage people with dementia;
- Deciding where to focus energies and how to prioritise (especially during the early stages of initiatives); and
- Resources, capacity, leadership and sustainability.

In the remainder of this section, we focus on the first two of these challenges. Engaging people with dementia meaningfully has helped DFCs determine their priorities (e.g. Kiama, 2015). Engaging a wide range of organisations should help increase the resources with

which to tackle these priorities (e.g. Heward, 2015). We consider the question of resources in the following section.

6.3 Engaging and securing broad partnerships

Involving health and social care, but just as part of the jigsaw:

> Approaches to dementia can be highly medicalised and focused on 'care'; so, it is necessary for work that is trying to promote Dementia Friendly Communities works with medical and care settings rather than ignoring them.

> (Programme Manager, Germany)

Having a local champion - typically a politician – can help to draw in a range of stakeholders, including those from healthcare and local government organisations. In the DEED project in Belfast (Seydak et al, 2015), the mayor helped to secure wide support for the work, including from the local authority. In Abbiategrasso in Northern Italy, the City Council passed a resolution for the active participation of the Deputy Mayor, the councillor for Social Services and some other officials in the Dementia Friendly initiative.

Findings from the group discussions with people with dementia highlighted the importance of considering health and care needs arising from health conditions other than dementia. Access to Dementia Friendly services to support hearing and sight loss, long term conditions and general health issues can be as important as access to specialist dementia services – sometimes more so.

Getting the size right:

A general consensus from the evidence is that DFCs are most effective when they cover a relatively small community: one interviewee suggested that an area with a population of no more than about 10,000 people over a distance of no greater than 10 kilometres in any direction worked best in their experience.

This was confirmed by the Norwegian organisation, Nasjonalforeningen for folkehelsen. Norway is a long, narrow country with many forests, fiords and remote rural areas. Its 5 million inhabitants are divided into 428 municipalities, many of which have less than 1000 residents. Whilst this can create other administrative challenges, it does seem to create quite favourable conditions for the development of DFCs.

A representative of the organisation explained: 'The size of communities is significant – we have generally found it is easier to roll out within smaller communities, especially where there are people who are very active'.

A practice example from Løten in Norway is outlined in Appendix 1 (1.9).

Engaging businesses and 'mainstream' organisations

A recurring theme from the existing published evaluations in this area is that face-to-face outreach work is most effective here, but that this can be extremely time consuming (e.g. Institute for Public Care, 2015; Henwood 2015). Leadership from the top can be a key enabler for larger chains and businesses: without this it can be challenging for local branches to release staff for training or display logos (IPC 2015). However, a local champion can really help to engage and motivate others:

> 'That lady used to be from the Santander Bank, she was right keen, and she got all the other branches involved, so it was spreading' (Person with dementia from our group discussion).

It is often someone with a personal connection to dementia who acts as the catalyst for a particular agency, business or group to get involved. Participants in Henwood's (2015) evaluation of the Skills for Care Dementia Friendly pilots in England complained how hard it is to get those outside of health and social care settings involved *unless* they have such a personal connection. The secret here – as one interviewee explained - seems to be time, combined with a mixed media approach and word of mouth:

> It's really hard to engage businesses. My wife and I dropped off 140 leaflets in person at the start invited all the local retailers to a meeting. Only one turned up – the funeral directors. But we now have 20 signed up. What worked? Not pestering them too much, I think. Things just very gradually started to build through word of mouth, personal connections and customer feedback.

> What works is that virtually everyone has some sort of connection to someone with dementia. Also what works is that we have had quite a bit of TV and newspaper coverage and people often get in touch after that. And then people start to notice their customers who might have dementia. The places that do have stickers start to notice that people are coming to them – the local bank has had accounts switched to this branch, people travel to the opticians here rather than use their local branch because they have heard they are Dementia Friendly and word gets around so others start to follow suit.

> So I don't think I would or could do it any differently if I was starting out again […] You just have to get the information out there but then be patient and keep at it but without repeatedly pestering the same people to the point where they hide when they see you!

6.4 Engaging people with dementia

Involving people with dementia in the creation and delivery of DFCs is important for a variety of reasons:

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- People with dementia and their carers have a right to be involved in decisions that affect them;
- People with dementia and their carers have the expertise, both in experience and aspiration. Understanding how they live their lives, what the barriers and opportunities are, and what people want to do should be the first step to developing an effective DFC;
- Involving people with dementia is important in terms of messaging. Not to involve people sends out entirely the wrong message and may easily reinforce stigma and the notion of people with dementia as people for whom things are done, rather than WITH whom.

However, Swaffer (2014), who is herself living with dementia, argues that:

The determination by governments and Alzheimer's societies and organisations around the world to promote DFC and dementia champions still mostly supports the 'about them, without them' position, which has the potential to further stigmatize people with dementia. To date, only a few people with dementia have been included in the discussions, planning and decisions about what makes a community, or organisation, Dementia Friendly.

(p.712)

This picture is confirmed in many of the evaluations to date. In Hampshire, England, the Institute for Public Care (2015) described the challenges of getting information to people with dementia and their carers, encouraging them to attend peer support groups and sustaining their involvement. The DEED project in Northern Ireland (Seydak, 2015) was unable to involve people with dementia in their local steering group structure.

In their article reflecting on the Dementia Friendly Pharmacy project in Austria, Plunger et al (2016, Chapter: 10) explain that – apart from the creative input of one person with dementia into the design of the project's logo, people with dementia had not been involved at all in the project.

However, there are projects in which people with dementia have played a key role in identifying priorities, making decisions, informing the content of awareness-raising and testing the success of changes to the physical environment.
Practice examples of engagement of people with dementia through the Dementia Engagement and Empowerment Project (DEEP) in the UK, and Dementia Friendly Kiama, New South Wales in Australia are detailed in Appendix 1 (1.10).

Mentoring, leadership and peer support for people living with dementia

Education needs to be given to people with dementia also that they can stand up and speak.
(Member of the European Working Group of People with Dementia)

The role of groups in providing mentoring, encouragement, and hope for people newly diagnosed and living with dementia should not be underestimated: this was a clear message

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from the discussion group with the European Working Group of People with Dementia. Many participants of this group described how meeting other people living well with dementia was the turning point in their lives post-diagnosis. Involvement groups have a significant role to play, not just as a vehicle for engaging in DFCs, but also to build the social capital and resilience of people with dementia more generally.

Experience of supporting the development of DEEP groups has shown that groups can falter if they do not have a focus: a meaningful activity to bind the group identity. The need to involve people in DFCs presents not just an ideal driver for the creation and support of peer groups, but also a clearly defined role and focus (DEEP evaluation, unpublished).

Alternative approaches to engaging people with dementia

Plunge et al (2016) reflected that, with hindsight, they should have sought to involve people with dementia at the start of the project, probably through an advisory group. However, they argue that the lack of an existing 'user involvement' culture in Austria and the subsequent lack of self-organising groups and 'dementia activists' makes this difficult. The context is similar in many countries across Europe: for example, the interviewee from Bulgaria explained that, although there are carers and volunteers linked to some of the patient organisations, there are as yet no peer groups and no collective voice of people with dementia.

So, what learning and ideas can be gleaned from the practice and research evidence for those trying to set up DFCs in areas where there are no existing groups of people with dementia?

- If there is a group of people with dementia operating in another area, commission them to come and audit your town, service, or building (as the West Yorkshire Playhouse did with the EDUCATE group in the Places section);
- Go out to existing groups, day centres, memory centres, anywhere where people with dementia already go and find ways to consult them about what helps or gets in the way of them participating in the community; this is the approach taken by the DFC project officer in Kent County Council, England.
- Seek out opportunities to speak to people one-to-one and outside of formal meeting structures, in places where they feel comfortable, such as their own homes;
- Link in with an existing project or person that already connects with older people and improve their communication skills in relation to dementia – they could feed in information about barriers and enablers for people with dementia in the local community. These 'community connectors' may be community workers, health or social care professionals, there may also be 'unusual suspects' – people making deliveries, or a café owner.

A practice example of how Community Ambassadors in County Wicklow, Ireland approached this issue can be found in Appendix 1 (1.11)

- Include opportunities to kick-start peer support groups for people with dementia (with and without their family carers) as part of a local Dementia Friendly initiative. Examples of this from the review have included: dementia cafes; activity-based groups (such as the Our Time arts-based group at West Yorkshire Playhouse); and simple gatherings at local pubs (e.g. Dementia Friendly Rothwell). Over time, there is evidence that these initiatives can start to build the networks, relationships, trust and confidence for the emergence of 'dementia activists', a campaign group, or perhaps just known individuals whose views can be sought. For example, one member of the Our Time creative group is now working to set up a DEEP group in Leeds so that people with dementia can come together to campaign for change in housing, health and other areas of life.

- Seizing opportunities: in the Community Pharmacies project (Plunge et al 2016), family care-givers were invited to attend consultation groups at the outset – their loved ones with dementia were 'looked after' during these sessions by members of a local Alzheimer's Association – this may have been a missed opportunity to engage people with dementia and find out their views about how to make the community more 'Dementia Friendly'.

In conclusion, the evidence suggests three levels of engagement of people with dementia in DFCs:

1. Making mainstream processes (such as Dementia Action Alliance meetings) accessible;
2. Supporting people to engage in mainstream processes (by helping a person with dementia to prepare for and contribute to a meeting); and
3. Offering parallel provision – such as an advisory or DEEP group or a focus group to consider specific issues.

6.5 Summary of key points and recommendations from this chapter

In order to establish an effective DFC, the evidence suggests it is important to:
- Establish a broad network, including partners from a range of businesses and services (i.e. not just health and social care), who can share responsibility for different work streams and actions. Ensure general health services (i.e. not just those with a dementia specialism) are engaged;
- Consider the size of the area: DFC initiatives seem to be most effective when they focus on relatively small communities, though local action can be coordinated strategically at a city or regional level;
- Face-to-face outreach and personal networking is an effective way of engaging shops and businesses but it can be very time-consuming and is more powerful where there is a personal connection to dementia and/or people with dementia and their supporters are directly involved;
- A multi-media approach, which might include local TV, radio and newspapers, leaflets, posters, public meetings and personal networking, seems to be most effective;

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- Ensure the voices of diverse people with dementia and their carers are heard within this network or alliance. There are several different ways of doing this, including:
    - Making the alliance or network meetings and decision-making processes accessible to people with dementia;
    - Supporting individuals to attend or feed in their views outside of meetings;
    - Developing a parallel advisory group of people with dementia which feeds into the alliance in a structured way.
- Recognise that people with dementia may need support and education if they are to participate meaningfully and if diverse voices (especially in relation to the stage of the condition and socio-economic status) are to be heard.

7. RESOURCES

In the context of reducing public sector budgets in many countries in Europe, the question of resources and DFCs can be controversial. Those involved in DFCs believe with a passion that a community response to dementia is vital. However, some of the UK interviewees highlighted the impact of substantial cuts to local authority funding on care services for people with dementia who need a lot of support: they warned that voluntary efforts to make communities more accessible cannot replace the need for high quality care and support by increasing numbers of people with advanced dementia. Members of the European Working Group of People with Dementia highlighted just how important personal financial resources can be in enabling the participation of people with dementia.

There are mixed messages in the evidence in relation to the financial resources needed to create successful DFC initiatives. On the one hand, much can be done in local communities with very little money if there are strong networks and enthusiastic volunteers. As one person who had provided support to a number of pilot projects advised: 'Don't let lack of money stop you from getting going with Dementia Friendly Communities'.

On the other hand, several interviewees felt strongly that funding is essential if DFC initiatives are to be built widely and, crucially, sustained. One interviewee was concerned that those providing statutory services tended to see DFC as a 'no-cost solution'.

This section presents the findings from research and practice in relation to the sorts of resources needed to promote, nurture and sustain DFCs, and how current initiatives are managing to access these resources.

7.1 What resources do DFCs need and where are they getting them from?

It needs a group of committed people who will persist in speaking and meeting with organisations, businesses and community groups to raise people's awareness […] to make contact and to maintain that contact.

(DFC Coordinator)

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The review identified time, energy and leadership as the key resources needed to support DFC initiatives. The projects reviewed have widely ranging budgets, with some 'grassroots' efforts run almost entirely on volunteer input, combined with small financial and in-kind contributions from members or local businesses.

For example, a retired volunteer and a former family carer explained that his work to promote a Dementia Friendly Rothwell is resourced through: volunteer input, sale of raffle tickets and a modest entrance fee for his monthly Saturday morning community breakfasts; and the support of local organisations and businesses. For example, the Church lets them use the parish centre for free and various local pubs reserve space and provide tea and coffee for weekly drop-ins. He explained: 'I think the key is that you don't need to go to great expense. You've just got to do it: get as many people involved as you can. People naturally offer to help.'

Elsewhere, DFC projects have received pilot – or in some cases ongoing – funding from national or local government sources, or from charitable trusts. For example:

- Kent County Council (England) has employed DFC Project Officers for the past four years, though the team has been reduced from four to two posts in response to significant cuts to local authority funding in England during this period; and
- Alzheimer's Society Ireland has received seven years' funding (2010-2017) from Atlantic Philanthropies to fund the development of DFC, alongside other aspects of the National Dementia Strategy.

A practice example of programme funding in Germany can be found in Appendix 1 (1.12)

In most cases, charitable or government funding seems to have been used to pay coordinators. Several of those interviewed believed this is essential if the impact of DFCs is to be maximised and sustained. However, there is a risk that, if and when the funding comes to an end and the paid coordinator can no longer be employed, these projects are even more vulnerable than those that have grown organically from local collective voluntary efforts:

'Leadership is important, but tends to dry up as the money runs out'

(Project Coordinator)

One interviewee explained how her role as coordinator at county level had evolved as projects had moved through different stages of their development:

At the outset, my role was to start building Dementia Friendly Communities – this was certainly the most labour intensive and the hardest stage. So I went out and did lots of initial research, speaking to peer support groups, finding out from people with dementia what they want and what the barriers are. As Dementia Friendly Communities have become more bedded in, my role has turned more into one of A&E (Administration and Enthusiasm!) – a lot of the local people involved are

residents and so I book meeting rooms for them and help to manage the flow of information through the Dementia Action Alliances in both directions.

Two interviewees who were involved in coordinating the efforts of a number of local projects expressed the view that 'seed-funding' of small local ideas and innovations (e.g. with grants of approximately 1000 Euros) has tended to have clearer outcomes and has created the most value for money.

Several interviewees expressed concerns that some private businesses paid only 'lip service' to DFCs. This might include displaying 'Dementia Friendly' stickers but not committing any resources to training staff or making changes. People with dementia told us about supermarkets that had introduced 'Dementia Friendly' measures but only on Tuesdays, or only in the run-up to Christmas, where there needed to be an ongoing commitment to making the store accessible, especially, in the UK, where businesses need to meet their legal requirements under the Equality Act 2010.

The input of people with dementia

As outlined in the previous section, the input of people with dementia and their carers is an essential resource for DFCs and one which needs to be properly supported. In the group discussions, people with dementia explained that the provision of travel expenses, a supporter, and accessible information is essential if they are to contribute effectively to focus groups, meetings and awareness raising events.

West Yorkshire Playhouse theatre explained they had commissioned (and paid) the EDUCATE group of people with dementia from Stockport (another area in the North of England) to come and conduct an access audit of the theatre. They explained that they are keen to develop and promote the consultancy of people with dementia in this way; those living locally may well be willing to be involved in audits and consultation for expenses only, but this principle cannot reasonably be extended out of area.

One interviewee (who has early onset dementia) also made the important point:

> You have to use what people bring with them – and this applies to people with dementia as well as everyone else. There is a risk that people assume the only thing people with dementia bring is their knowledge and lived experience of dementia, but you need to find out what they did before, what their strengths and skills and contacts are and build on these too. You still are who you are. So it's about bringing that breadth of experience.

> (Person living with dementia, England)

Leadership and support

In a number of European countries, a charity – usually, though not always, a specialist Alzheimer's association – has taken on the role of promoting, coordinating and monitoring DFC initiatives.

In Germany, a representative of the Federal Government explained that they plan to appoint an organisation that can work across the country to help nurture and sustain this work: they do not believe this is a job which the government itself can do well.

Approaches to this issue in Scotland and England are presented as practice examples in Appendix 1 (1.12).

In Norway, Nasjonalforeningen for folkehelsen explained that they have made a conscious decision not to ask for output data from those municipalities which have committed to becoming Dementia Friendly. Once a municipality has signed an agreement with them:

> We leave a lot of the work to the local groups: we give them some information on where and how they can start, but they need to take responsibility for it. Some rise to this; others struggle more. This is partly about our resources but it is also about trying to build a strong campaign that can live a life of its own without substantial central administration. We are keen to support local initiatives to bubble up from the ground, rather than roll-out a rigid top down approach'.

Examples of the (non-financial) resources and support which some of these national 'infrastructure' organisations offer include:

- Training materials to use in awareness raising sessions;
- Stickers and other logo branded materials;
- Brochures or leaflets which can be handed out to shops and other organisations;
- Guidance and templates for local projects;
- Mechanisms for sharing learning:
    - Alzheimer's Society (England) is building a database of good practice;
    - Alzheimer's Ireland has facilitated meetings of a Learning Forum, so that pilot initiatives can network with each other and cover topics of interest.
- Awards ceremonies to celebrate achievements and share good practice.

7.2 Monitoring and evaluation

Many of those interviewed who were involved in local DFC initiatives were very aware of the importance of gathering evidence of impact so as to build a 'business case' to secure resources and commitment in the future. Some have already been evaluated; others – like the Federazione Alzheimer Italia - told us they were working in partnership with a local

research institute from the outset, conducting baseline surveys of people with dementia and their carers, and collecting feedback questionnaires following awareness raising sessions.

However, a number of challenges were raised in relation to monitoring and evaluation:

- Resources were a key barrier: both in terms of commissioning an external organisation to conduct a formal evaluation, but also in terms of supporting community-based projects to record their activities and gather evidence of impact. One professional who had been involved in a supporting a number of local pilots commented: 'If we want to capture and meaningfully measure impact from these kinds of initiatives, we need to invest in the people doing it'.
- Understanding what to measure: respondents reflected on the challenge of deciding exactly what they should be measuring and how, given:
    - The complexity of trying to achieve culture and system change and establish causality within this;
    - The challenge that, while some projects have a clear group of participants with dementia, others do not – they are seeking to remove barriers within mainstream society;
    - Challenges in relation to timescales: pilot projects typically receive 1 to 3 years' funding, yet many DFCs have very long term objectives; and
    - The pressure to produce quantitative evidence of change can also be problematic; it can mean that projects focus on gathering data about outputs (rather than feeling confident about collecting and recording 'anecdotal' evidence and stories of change). Also, as Nasjonalforeningen for folkehelsen pointed out, the number of people attending a session might be really small, but it could nevertheless have a significant impact (and vice versa).

Despite these challenges, there have been some attempts to develop monitoring tools for DFC initiatives. Please refer to Appendix 1 (1.13) which details how Alzheimer's Society Ireland developed a monitoring tool for its DFC pilot project.

Based on the evidence gathered in this report, the review team propose a set of indicators, presented in the final chapter.

7.3 Longer term sustainability of initiatives

There were a number of key messages and recommendations from the evidence regarding the best approaches to sustaining DFCs. These included:

- Building strong local alliances in which responsibilities are shared;
- 'Mainstreaming' activity into commissioning frameworks and local action plans;

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- Demonstrating the 'business case' (in both private and not-for-profit organisations) for activities, ideally strengthened with evidence of impact;
- Working to ensure that 'dementia-friendliness' is based on disability rights;
- Building (the capacity of) political groups of people with dementia;
- Ensuring that dementia (including the lived experiences of people with dementia and their care-givers) is a regular topic on ongoing training programmes; and
- In England, there has been some discussion about how Dementia Friendly activities could be embedded in social prescribing – an emerging mechanism through which doctors can refer people to (and fund) a range of 'social' prescriptions, e.g. to attend leisure or social activities.

7.4 Summary of key points and recommendations from this chapter

- DFCs receive a huge range of financial resources: some 'grassroots' efforts run entirely on voluntary effort; others receive funding from government/ national charities;
- Time, energy and leadership are the key resources, though the input of people with dementia requires some funding if it is to be effective and sustainable;
- In some countries, a national charity (sometimes with government funding) is supporting a network of DFCs, providing them with: publicity and awareness-raising materials, branding, guidance, mechanisms for sharing learning, awards ceremonies, etc.
- Some DFC initiatives have been evaluated, however barriers include: resources (including the capacity of those at grassroots level to collect monitoring data) and the methodological challenges related to measuring culture and system change.
- Key factors promoting the sustainability of DFCs include: a broad and strong alliance, structures to build the capacity of groups of people with dementia, and the 'mainstreaming' of initiatives into day-to-day business by emphasising legal rights and benefits to businesses and by embedding them into wider strategies and training programmes.

8. CONCLUSIONS

In chapter 3 of this report, the following definition was proposed:

> **In a 'Dementia Friendly Community', people with dementia are included and respected. Citizens, organisations and businesses work together to remove the barriers which stop people with dementia and their supporters from participating in community life.**

In this concluding section, the key messages from the evidence review are synthesised into a suggested model for successful DFCs. The evidence reviewed suggests that good outcomes are most likely when the processes and inputs contained within this model are in place. In formulating this model, the research team has attempted to:

- synthesizing data from interviews, group discussions and online survey feedback in relation to the four existing definitions;
- Draw on the learning from this evidence review;
- Encompass the core features of existing models (eg. the Alzheimer's Society recognition process in the UK) and
- Provide a structure which is flexible to and driven by local needs and circumstances.

8.1 The structures and processes at the core of an effective DFC

At the core of the model is an alliance (a 'Dementia Action Alliance' or similar).

This 'coalition of the willing' brings together those in the community with a role to play in making it more accessible to people with dementia: the 'citizens, organisations and businesses' mentioned in the definition.

The exact composition of the alliance may vary, but it should always include people with dementia and their carers, for whom there should be a range of ways to be involved. Both health and social care organisations and other 'mainstream' services and businesses should be involved, alongside local citizens. A 'change agent' (such as a charity, which is able to offer leadership) can also play a useful role in supporting and sharing learning between local initiatives.

The alliance provides leadership and vision. It should establish and communicate the **core values** underlying the DFC which, according to the findings of this review should include:

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- Being asset-based: building on local resources and the strengths of individuals, including people with dementia and their carers;
- Removing barriers for people with dementia from mainstream services and provision;
- Taking a rights-based approach
- Placing co-creation with people with dementia and carers at its heart

The alliance has a core function in **planning** the delivery of DFC. This will include:

- Finding out about the current experience and aspirations of people with dementia and carers;
- Working with people with dementia and carers to establish key **outcomes;**
- Identifying both community assets and obstacles in achieving the desired **outcomes;**
- Setting priorities in terms of **outputs.**
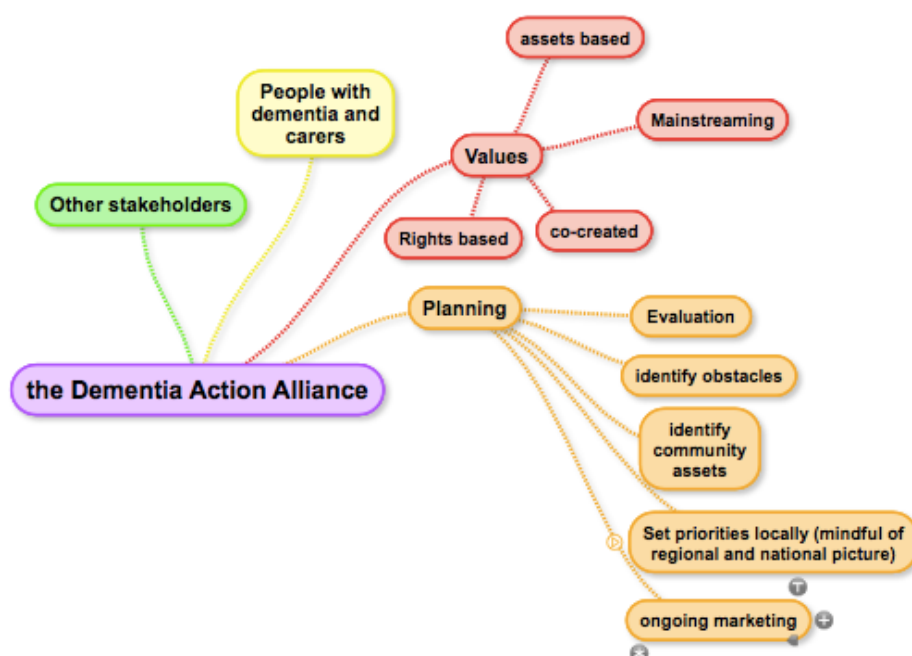
This should be encapsulated within a coproduced evaluation strategy that enables outcomes to be linked to outputs via a set of SMART (Specific, Measurable, Achievable, Relevant, Time-bound) indicators that allow progress to be reviewed and ongoing actions fed back into the planning cycle. Section 8.4 below considers the development of indicators in more detail.

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8.2 Potential areas for action under local priorities

While the specific processes and inputs above are likely to be common to most successful DFCs, the outputs will vary, depending on local priorities and resources.

In order to set priorities, the alliance should consult with people with dementia and their supporters to find out:
- o How they currently use the community;
- o How they would like to use it;
- o What the barriers are;
- o How they could be reduced or removed; and
- o How people with dementia could be involved in making this happen.

Priorities should be largely driven by local needs and aspirations but should also be mindful of national and regional drivers.

Specific outputs across DFCs are delivered within eight intersecting areas of community life[4]:

1. Arts Leisure and Recreation
2. Shops and businesses
3. Schools and colleges
4. Faith, voluntary and community groups
5. Emergency serves
6. Health and Social Care
7. Housing
8. Transport

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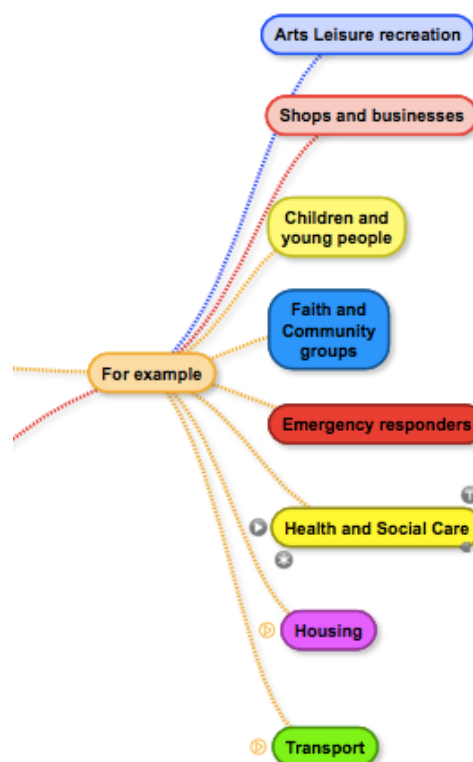
[4] NB these are consistent with British Standards Institute, (2015) PAS 1365:2015 Code of practice for the recognition of dementia-friendly communities in England, BSI Standards Limited, London.

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The activities (outputs) that take place within these areas will vary, but fall broadly into five intersecting areas of activity (the 'cornerstones' we introduced in chapter one of this review):
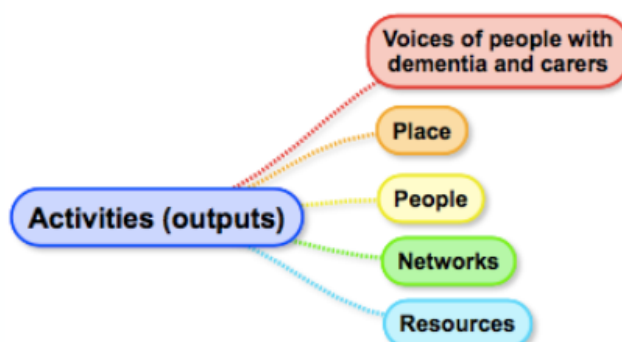
Voices of people with dementia and carers - how are people with dementia and carers involved and heard?

Place - how accessible are the buildings, public spaces and written information to people with dementia?

People - are there opportunities for raising awareness and sector specific training?

Networks - how do organisations and service work together with others to support people with dementia?

Resources - how can resources be focused in a way that increase the accessibility mainstream services for people with dementia, builds resilience and provides a community-based response?

The full model is shown in the diagram overleaf:

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DFC MODEL

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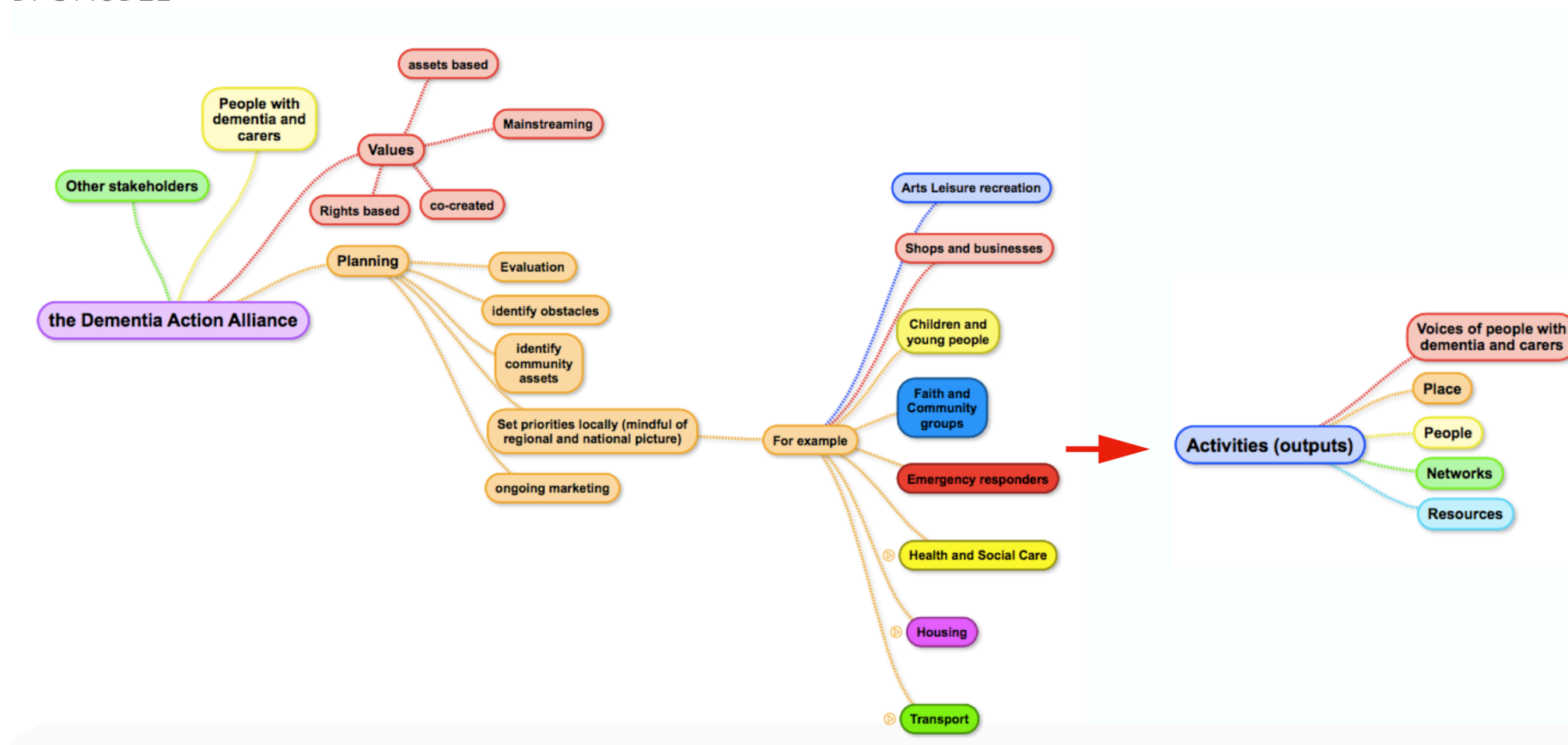
8.3 Nurturing and sustaining DFCs

Continuing to engage and expand membership and building sustainability beyond initial funding are ongoing challenges to be addressed by effective DFCs.

The evidence gathered for this review suggests that sustainability is best promoted where DFCs:

- Are based on a broad alliance, which includes people with dementia and in which responsibility and leadership is shared;
- Activities are mainstreamed into local plans, strategies and training initiatives;
- There is a long term commitment to this agenda, including political commitment; not a belief that a DFC is something which can be quickly achieved;
- Evidence is gathered to build a 'business case' for activities;
- Opportunities to learn and share experiences from other projects and nations are maximised; and
- The focus is on bringing the Dementia Friendliness agenda in line with the disability rights agenda.

8.4 Developing indicators to evaluate the success of DFCs

The World Health Organisation (WHO) has published comprehensive guidance around developing indicators for the evaluation of age-friendly initiatives (WHO 2015), based on the relationships between:

- Inputs - the resources and structures which act as enablers;
- Outputs - the activities undertaken to create change;
- Outcomes - the short and medium term changes to the physical and social environment; and
- Impact - the longer term changes as a result of DFC to health and wellbeing.

WHO focus their framework on outcomes and impact - arguing that aspirations for outcomes and impact will be broadly similar between initiatives - whereas the inputs and outputs utilised to achieve them will vary between projects. This structure was also adopted and adapted by Kiama, Australia (which has undertaken one of the most comprehensive evaluations of DFCs to date) (Dementia Illawarra Shoalhaven 2015).

The table on page 54 links the WHO framework to the model for effective DFCs proposed by this review.

Impact on health and social care service usage

A key question for DFC initiatives – especially as they argue for mainstream government funding – is whether and under what circumstances they can make an impact on health and/ social care usage, and ultimately costs. The evidence base on this question is, to date, extremely limited. For example, IPC (2015) found, in their evaluation of DFCs in Hampshire, England, that it was too complex (and the timescales had been too short) to attempt to unpick causality in relation to the impact of the DFC initiatives on service pathways for people with dementia. Henwood (2015) suggests a number of Key Performance Indicators for DFCs in relation to the provision of health and social care, such as early diagnosis rates, ambulance pick-ups for people with dementia, and more referrals to social care services by doctors following early diagnosis. However, this review did not find published evidence of such impacts and also noted a gap in terms of articulating the specific mechanisms – or Theory of Change – through which such impacts might occur.

Such a Theory of Change in relation to improving early diagnosis rates might, for example, set out what is already known about barriers to early diagnosis in a particular setting and specifically which of these problem(s) a DFC initiative might tackle and how. For example, if there is a particular concern about low diagnosis rates amongst men in a particular area, a DFC might include awareness raising activities in clubs, workplaces and settings which men commonly use and focused work with doctors and other professionals in that area.

Frequency of measurement

The frequency with which indicators should be measured will depend on the type of indicator and the pace and intensity of the DFC initiative.

Input and output measures should be continuously monitored and could be meaningfully reported quarterly, bi-annually or annually, depending on the pace and intensity of the initiative and the duration of the pilot or funding period.

Outcome measures should ideally be measured at baseline (e.g. of participants' knowledge and attitudes before an awareness-raising session, or of people with dementia's assessment of the accessibility of a venue before – and to inform – any changes) and following the intervention.

If practical, follow-up with these groups at, say, 6 months after the intervention would give an insight into the impact on individuals and their behaviours, but this will depend on the nature of the intervention.

Measuring longer term impact on the wider community is more challenging: a baseline survey of public attitudes might be undertaken at the outset of a DFC initiative, with follow-up at perhaps 2- or 3-year intervals.

Measures for testing the effectiveness

Additional measures to employ during the testing phase of Workpackage 7, and to measure future impact assessment, have been proposed by Workpackage 3 of the EU Joint Action. Members of Workpackage 7 have given an initial assessment of the suitability of these measures, and will give further consideration to their application for the pilot stage. The list of these indicators and the initial assessment of their suitability can be found in Appendix 3.

Indicators for each of the four 'cornerstones' of People, Place, Networks and Resources, based on the evidence reviewed and appraisal of the methods used in existing DFC evaluations

	Inputs	Outputs	Outcomes	Impact
Description	Structures and resources which enable DFC, e.g.: involvement of people with dementia multiple stakeholder alliance financial and human resources high level political commitment	The activities undertaken to create a DFC, including interventions in: the physical environment the social environment and within any of the 8 output areas outlined in the DFC model (transport, housing, Health and Social Care, Emergency responders, Faith and Community groups, children and young people, shops and businesses, Arts Leisure recreation	Improved accessibility of public spaces and buildings improved accessibility of information improved participation in or access to people with dementia across the 8 output areas. increased positive social attitudes towards people with dementia	The long term changes to health and wellbeing brought about as a result of DFC. These might include: health-related quality of life satisfaction with life level of loneliness satisfaction with social relationships
Types of Measures	Process evaluation Indicators can be binary (yes/no) or measure the level of availability Focus on measuring inputs most clearly linked to a broad range of outcomes.	Will vary from project to project but may include: evaluation of processes monitoring of activities changes in policy media coverage number of events or meetings attendance levels	Measures should include: Data from formal sources, e.g. government/ service provider data-sets, and Self-reports from people with dementia/ carers.	Challenges here include demonstrating causality in relation to the benefits of DFC on health and wellbeing or people with dementia and caregivers. However, developing impact measures for DFCs can support cross sector working to achieve common goals. In this sense perceived benefits by end-users can be collected in qualitative terms as proxies together with quantitative testing measures.

Alignment of Indicators with World Health Organisation's work to develop Age Friendly indicators

Inputs	Outputs	Outcomes	Impact
NETWORKS	PEOPLE	PEOPLE	
Involvement of people with dementia • Alliance meetings and information are accessible and/or there is a parallel involvement structure • People with dementia influence priority-setting and decision-making	• Awareness-raising activities (e.g. type, method, length/depth, numbers reached – e.g. participants, web hits, circulation – and where possible their profile	• Self-reported improvements in knowledge, attitudes, skills, behaviours	• Recorded incidents of discrimination, mistreatment, abuse of people with dementia • Public attitudes towards (people with) dementia
Multiple stakeholder network/ alliance • There is an alliance (or equivalent) whose members are committed and are drawn from diverse backgrounds/ organisations • Level of dementia awareness and shared values amongst those involved	• Input of people with dementia in developing/ delivering materials	• Reports from people with dementia/ their carers and/or managers/ colleagues confirm these improvements	• Media portrayal of (people with) dementia • People with dementia reporting that they use mainstream services, participate in and feel part of their local community
RESOURCES	PLACE	PLACE	
Financial resources • How much financial resource has gone into the DFC work and how has it been spent?	• Practical steps taken to improve accessibility of physical environments and/or information	• Services and businesses report increased/ improved usage by people with dementia and their carers	• Quality of/ satisfaction with life • Loneliness/ satisfaction with social relationships
Non-financial resources • How much non-financial resource (e.g. time, facilities, etc) has gone into the DFC work and how has it been used?	• Input of people with dementia and their carers in identifying barriers and testing improvements	• People with dementia and their carers report improved accessibility of public spaces, buildings and/or information	• People with dementia can live better and longer in their own homes with reduced support from services
Political commitment • What is the level of political commitment in the DFC and its values? • What difference has this made?			

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8.5 Benefits

Perceived benefits and outcomes of an effective DFC, drawn from the analysis of this report, have been extracted in the below table, and classified as qualitative or quantitative. These benefits will be tracked and monitored in the pilot stage of the EU Joint Action Workpackage, with the aim of ultimately informing a best practice approach to facilitating the monitoring and delivery of benefits from DFCs across member states:

Group/ environment	Main perceived benefits/ outcomes							
For people with dementia and caregivers	Improved accessibility of public spaces, buildings, transport and information.	QUAL	Improved quality of life. Improved social relationships and reduced loneliness. Reduced experience of discrimination.	QUAL	Increased use of mainstream services. Improved ability to have a sense of 'normal life' such as going to the shops, cafes and sports clubs.	QUAL/ QUANT	Increased participation in community life. Increased participation in activities such as work, volunteering and peer mentoring.	QUAL/ QUANT
For society	Increased awareness and change in attitude and behaviours towards people with dementia.	QUANT/ QUAL	Reduced stigma and fear surrounding dementia.	QUAL	Improved 'culture of care' in which people in the community support people with dementia.	QUAL	Improved environment for all as what makes environments better for people with dementia will also make them better for everyone.	QUAL

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For professionals, services and businesses	Increased empathy, skills and confidence to respond positively and supportively to people with dementia and their caregivers.	QUAL	Improved usage of services by people with dementia and their caregivers.	QUANT/ QUAL	Increased and improved usage of businesses and by people with dementia and their caregivers.	QUANT/ QUAL	Improved understanding how to practic support peopl dementia.
For the economy	Reduced costs of care as people with dementia are supported to live better and longer in their own homes with reduced support from services.	QUANT					

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8.6 Limitations of evidence review

There are a number of limitations to this review:

- There was insufficient time and budget to review literature and information which was not in English language. To mitigate this as far as possible, we drew on the findings of the recent EFID review (Williamson 2016) (which had been able to translate primary and secondary data more proactively). Our online survey/ invitations to interview included the offer of translation/ interpretation and this was taken up on several occasions.

- Many of the countries contacted were at too early a stage in their DFC development to provide us with any information, let alone formal evaluations, though evaluations are planned or in process. Northern European countries were generally more advanced in terms of the development and evaluation of DFCs, therefore we recognise that the UK, Norway, the Netherlands and Germany are over-represented. The team sought to counter this with practice examples from Spain and Italy and with qualitative feedback from participants from a range of countries where the response to dementia is at a much earlier stage of development (e.g. Bulgaria, Portugal (Madeira), Greece, Czech Republic). These conversations provided a different frame of reference for the interpretation of evidence from elsewhere. This also meant that we looked further afield – to Australia, Japan and the US, where there is a well-established community of DFC practice.

- Given the time constraints of the project:
  - It was only possible to run the survey for 3 weeks, which may have restricted the response – the survey was mailed out to an email circulation list of those with an interest in DFCs drawn from across the EU, however, the team did not have any additional contact or role information so we were dependent on these contacts to act as 'gatekeepers', circulating the link to the survey/ completing it.
  - It was not possible to return to participants (including people with dementia) to iteratively test the model and definitions proposed; to mitigate this, we shared the draft report with those who contributed to the review, including circulating the easy read and full versions of the report with the groups of people with dementia we had consulted. We were not able to collect feedback systematically.

- In parallel to this review, the World Health Organisaiton (WHO) is currently developing a Dementia Friendly Initiatives toolkit with the aim to provide practical guidance to policy makers and programme managers in assessing, improving and scaling up initiatives to create a dementia-friendly society. Given that this activity will involve and benefit EU Member states, and the common ground it will cover in relation to Work Package 7 of the EU Joint action, to would have been beneficial to coordinate the two activates to ensure that synergies were maximized.

8.7 Recommendations

The evidence review lends itself easily to the development of the second key component of Work Package 7 of the EU Joint Action (D7.2) - a practical DFC tool kit that will subsequently be tested in practice in DFC pilot sites in EU Member states.

Key deliverables for the second phase of the project will be as follows:

- Weighing up the number, desirable characteristics of, and geographical and demographic spread of, the pilot sites.
- Securing buy-in and sign-up from pilot sites
- Producing training and support material for pilots
- Running the pilots over one year
- Monitoring the pilots in-year
- Evaluating the pilots at end-of-year
- Reporting on, and dissemination of, the learning from the testing of the tool kit in pilot sites

The final task will be to produce a high-quality report (on the application of the toolkit, and the learning from testing it through the pilot sites) that can be easily understood and implemented by all EU28. This will be brought to the attention, through multi-media channels, of all interested parties, including governments and policy-makers, local system leaders, people with dementia, their carer-givers and families, NGOs, academics and more. The intention would be to have produced and disseminated this report by December 2018.

Based on the evidence reviewed for this project, the research team make the following recommendations in relation to the development of the pilot stage of the EU Joint Action Workpackage:

- That the pilots follow, test and refine the model proposed;
- That the pilots ensure the input of people with dementia throughout and maintain their focus on the value base outlined within the model: these should form key selection criteria and projects should be asked regularly to demonstrate how they are meeting these criteria during the funding period;
- For the tested toolkit to be most amenable to diffusion and successful adoption throughout EU28, the pilot sites should cover both large and small populations, be set in a mix of urban and rural settings and be spread across a number of countries with different cultures, languages, economic circumstances and health and social care systems. The pilot sites should also constitute a mix of fledgling and more mature dementia friendly communities. This should help to overcome some of the limitations of this review, in the sense that evidence has been drawn from more mature DFCs, typically from Northern European Countries. It is understood that the

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current proposed selection of pilots looks to address this by exploring pilot sites in Greece (with a more rural focus), Bulgaria (a fledgling DFC) and Italy.

- That projects are required at the start of the funding period to develop an evaluation framework which sets out a Theory of Change for their initiative (which problems they plan to tackle and how) and identifies relevant indicators and a plan for measuring these.
- That Work Package 7 members work to synergise the model proposed in this report with the Dementia Friendly Initiatives framework and toolkit being developed by the WHO, to arrive at a toolkit that maximises evidence drawn from both, and gives a consistent picture of best practice. Employing this synergised toolkit would accelerate progress and timescales as expertise on specifications and testing, developed through the WHO activity, could be capitalised upon in the pilot stage.

The review identified a significant number of evaluations which are in process, suggesting that a follow-up evidence review might usefully be conducted in approximately two years' time.

APPENDIX 1

PRACTICE EXAMPLES

1.1 People: Awareness-raising and training sessions

Dementia Friends, UK

The Dementia Friends campaign is run by Alzheimer's Society England and aims to increase the general public's understanding of dementia. Anyone can become a 'Dementia Friend', either by attending an awareness-raising session in their workplace or local community or by registering online, watching a short video in which a woman living with dementia talks about her life and experiences, and receiving an information pack through the post. The initiative now has over 1.7 million Dementia Friends across England and Wales and has set a target for 4 million by 2020. The programme is due to be evaluated in the near future. https://www.dementiafriends.org.uk

Dementia Friendly Community Pharmacy, Austria

This participatory action research project between carers and workers in community pharmacies took place in two very different settings in Austria: Vienna and rural Lower Austria. Family carers of people with dementia reported different challenges in these two areas during initial engagement groups – in the city, they felt they were fighting bureaucracy to access services; in the rural area, the challenges were related to a lack of services and the distances they needed to travel to access them.

In both settings, carers felt that the community pharmacy could be used as a 'space for information and networking, especially as a place to talk about dementia and make the topic visible in the community'. The projects have included training for pharmacy staff in dementia awareness and issues linked to medication; the provision of information through leaflets and awareness raising events; and the development of a network of services, businesses and community groups (Wegleitner et al., 2016). The project has been evaluated; though the report has not been published (Zepke et al 2015).

Spain: Carers' Education Programme

The Expert Patient Programme in Catalonia has been extended to include family care-givers of people with dementia, with the aim of increasing their awareness of dementia and allowing for the exchange of knowledge and experience between care-givers – outcomes which have been demonstrated from the evaluation of the wider Expert Patient Programme for those affected by other long-term conditions (Claveria Guiu et al 2016).

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Locally recruited carers work with other carers to raise awareness and help them to 'see that change is possible'. The project works with carers 'where they are' and professionals are not allowed in the sessions.

1.2 People: Media

A key message from both published evaluations (e.g. Institute for Public Care 2015) and interviews is that positive media representation and awareness raising running alongside DFC activities can boost engagement and awareness considerably. A number of resources which aim to challenge common myths and assumptions in relation to dementia have been created and disseminated as part of DFC initiatives.

For example, as part of their work to create a Dementia Friendly Abbiategrasso, Federazione Alzheimer Italia has published a video interview with Father Giancarlo Politi, who is living with dementia. This the first time someone with dementia has spoken publicly in this way in Italy, where the taboo surrounding dementia is still strong in many communities. The padre describes the challenges of his daily life since he developed dementia, but also describes the huge support he receives from his family and community.

He asserts the ongoing identity of people with dementia and their right to come forward and be heard. The award-winning video has been published on You Tube and has received over 100,000 'likes'. An interviewee from Federazione Alzheimer Italia explained how difficult it is to get the message across that people with dementia can and should participate in community life. He explained: 'This video is the first of its kind in Italy and we hope that it will start to break the glass for people with dementia'.

The film is available (in Italian only, though there are plans to provide English subtitles) at: https://www.youtube.com/watch?v=N_KHCnf0AW8

In a very different style, FreeDem Films in Ireland have produced a series of short animated films about dementia and brain health, including one entitled, 'How can we include people with dementia in our community?'. This is part of the Neil Programme at Trinity College Dublin, Ireland (http://www.tcd.ie/Neuroscience/neil/), and can be viewed at: https://vimeo.com/76537799

The Pioneer Group are a group of people with dementia who helped to produce a campaign to tackle stigma as part of the Dementia Friendly Edinburgh work (in Scotland). The campaign posters focused on six key pieces of advice to the general public:

1. Learn the facts
2. Help me join in
3. Use kind words
4. Talk to me
5. Be patient
6. Be a friend

(Henderson, 2015, p.7)

1.3 People: Intergenerational work

Many of those who responded to the online survey and took part in phone interviews felt that intergenerational activities undertaken within DFCs were very valuable:

> I view DFCs as future-proofing our communities and I think this is a key driver for many of the people involved at a community level. Young people get involved because they have seen a family member, etc. – so a lot of the outcomes we are looking for are very long term. It's very long term preventative work.

(DFC Coordinator, England)

Kaiser and Eley (2017) describe a community farm which has been developed next door to De Blinkert – a nursing home in Haarlem, Netherlands – as a result of a local partnership, including the municipality, the nursing home, a number of other organisations and local individuals. The farm sells weekly vegetable boxes to members of the local community and acts as a hub for inter-generational activity involving people with dementia. Volunteers of all ages work alongside people with dementia (both nursing home residents and those living in their own homes nearby) to undertake farming tasks; and people of all ages come to enjoy the animals and the outdoors.

In Japan, the Fujinomiya project, Bridging Communities; Sharing Our Memories, run by high school students, supports intergenerational interaction based on the history of the local area using photographs. Students are also involved in internships in which they record photographs and memories of a person with dementia by speaking to them and compiling a life history of the person.

In England, the Department of Health funded a pilot dementia education project in 22 primary and secondary schools in add duration of project. The evaluation (Atkinson and Bray, 2013) demonstrated positive outcomes for participating students, including improved awareness and reduced fear of dementia. It also identified the following key learning points:

- The 'depth of impact' and the degree of enthusiasm from students was 'surprising';
- Projects highlighted the training needs of teachers in relation to dementia and the importance of forging partnerships with community organisations;
- The projects that had the most impact maximised the ownership by pupils and included opportunities for them to meet and get to know people with dementia;
- Follow-up support for pupils and teachers with lived experience of dementia and accessibility for participating people with dementia were, however, essential to do doing this effectively.

1.4 People: Enabling people with dementia to make a contribution

The importance for people with dementia of being able to continue making a contribution was a key theme emerging from both the primary and secondary evidence reviewed. In the words of one member of the European Working Group of People with Dementia:

'Dementia is a small part of my life. I can contribute in other ways to my community. My life is not just around dementia: stay involved with things you were involved in before dementia!'

This section highlights some of the international projects which support people with dementia to make an active contribution, both to helping others with dementia but also in other areas of their lives, i.e. outside of their knowledge and experience of dementia.

'Side by Side': a workplace project for people with early onset dementia, South Australia

This innovative project was featured in ADI's Global Developments (2016) DFC examples. It is a partnership between a large hardware store (Bunnings Warehouse) and a respite provider for people with dementia (Life Care). Since 2011, a small group of seven people with early onset dementia (aged 50 to 65) have been supported to work alongside employees during a four-hour weekly shift at the store. They have a briefing and de-briefing session together at the respite cottage before and after the shift. During the shift, they are supported by 'Work-buddies' – staff at the store who have volunteered and been trained for this role. Information about the project and about dementia is also distributed at the store via an information booth; but it is the regular contact between people who have dementia and the store's staff and customers which has really helped to break down barriers and challenge stigma (Robertson, 2013).

The pilot has been formally evaluated by University of South Australia (Robertson and Evans, 2015). Over time, participants' proficiency, confidence and work duties increased:

where the relationships with 'work buddies' had started out unequally; they became genuine partnerships. 'Contributing to society' was one of four desired outcomes that participants identified at the outset. As one explained later when describing their work at the store: 'you feel you can give back to the community, and you can contribute' (Robertson and Evans, 2015, p.2335). The project reflects a number of key principles of the DFC movement, i.e.:

- It engages people with dementia in meaningful activities within the workplace and 'real world', rather than through community-based services: this has helped to 're-establish their connection to the community' (Robertson and Evans, 2015, p.2338);
- People with dementia have built varied social networks naturally through working side-by-side with staff and each other and through serving customers, which builds their resilience and helps to break down the stigma attached to dementia.

DemenTalent, Netherlands

One of the finalists in the 2014 round of European Foundations' Initiative on Dementia's funding for DFCs also made use of volunteers. The DemenTalent project worked with volunteers with dementia to clear scrub, maintain woodland and buildings. Based in the City of Apeldoorn in the Netherlands, project participants with dementia reported positive outcomes, for example saying:

'Finally, I feel a part of the community'

'I don't have fear of failure anymore'

'I can do something for the community'

'I can use my hands'

Maidstone Mentors, England

The idea for this peer mentoring scheme came from a member of the Maidstone Peer Support Group for people with dementia. He and other members of the group said that once they had received a diagnosis they had felt completely alone, 'like stepping off a cliff', not knowing where they could go or who they could speak to. He began by giving his phone number to his doctor and telling him to pass it on to anyone else who was referred to the memory clinic: but he did not receive any calls. The group then worked with the Alzheimer's Society to set the project up formally. This has included piloting and evaluating it; promoting it and providing training and support to volunteer mentors. Mentors now attend the Memory Clinic's post-diagnostic course to introduce themselves and talk to newly diagnosed people. The mentors:

- Listen and do not provide advice;
- Share their own experiences of being diagnosed and finding support;
- Tell people what is available locally; and
- Signpost people to someone at Alzheimer's Society if they feel unable to assist.

(Kent County Council, 2016)

1.5 People: Providing support to people with dementia to access community life

One-to-one support is cited in the UK Prime Minister's 2020 Challenge (Department of Health, 2015), along with peer group support, as an effective intervention post diagnosis. The Local Government Association guidance on DFCs (2015) also makes frequent reference to local authorities' roles in supporting people with dementia to stay engaged in their communities. Family care-givers clearly play a key role here - taking the person with dementia swimming, to the theatre or out shopping; but there are ways in which the local community can provide an additional resource.

One such service is Side by Side - provided by Alzheimer's Society in England, Wales and Northern Ireland. The service provides volunteers to support people with dementia to 'keep doing the things they love…and feel part of their community' (https://www.alzheimers.org.uk/sidebyside)

The person who runs the service in Worcestershire was interviewed for this review and described the case of one man whom the service had supported. Both he and his wife were very withdrawn when she first met them. However, by working with a volunteer and getting involved in everyday things like shopping and going for coffee she described how they have both become 'different people' – the man said:

"I realised I can still be me."

1.6 Place: Enabling people with dementia to reclaim their rights in the public realm.

Paul's Club in Vancouver, Canada, is a social group of people who have early onset dementia and volunteers (who do not). After eating lunch in a local hotel, the group's typical routine is to go out for a walk together around their local neighbourhood. In their evaluation[5] Phinney et al. (2016) identified the following significant impacts of this simple act of going for a collective walk:

- The focus is kept off dementia: walking is not a 'programme' or an 'intervention', but an enjoyable pastime of a group of friends – members of a club, not clients of a service. The workers which the group meets – in the hotel and the local ice cream kiosk – are focused on making everyone comfortable and welcome, not on their impairments (as health and social care services have a tendency to do);
- It creates a sense of belonging: being a member of the club and walking together is really important to everyone, yet there is movement, freedom and flux as people form little groups and walking partners naturally change;
- It claims a place in the community: business owners have learned how to adapt and serve the group; members of the group greet and speak to dog walkers and parents of young children. This gives members of the group an opportunity to make a contribution (one person always brings dog treats!) but is also: 'Bringing the message into the broader community that it is possible to live well with dementia' (p.388).

Although not explicitly badged as being part of a DFC initiative, this example highlights some important principles:

- The group is a specialist group for people with dementia but it is more of a coming together of equals than a 'service';
- The emphasis is on getting out into normal, everyday places, not creating segregated places for people with dementia.

As a result of this, it can be said to promote the 'citizenship' of people with dementia.

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[5] Through 400 hours of participant observation and 'go-along' interviews, and group discussions using photos taken on walks as visual prompts

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1.7 Place: Accessibility

Making transport accessible

A number of DFC initiatives have included training and awareness raising for transport workers. For example, the largest bus operator in the Netherlands has been working with Alzheimer Nederland to train their staff to recognise and help customers with dementia in a friendly and appropriate way. **Alzheimer Nederland** strongly believes that creating awareness around dementia alone is not enough. Providing people with the tools and skills on how best to interact with someone living with dementia is also an important element of building dementia-friendly communities (Alzheimer's Society 2017).

The **Scottish Dementia Working Group of People with Dementia** have produced a leaflet giving tips on using different forms of public transport for others with dementia. The guide highlights the rights of people with dementia to request free assistance at airports and on the UK train networks. http://www.sdwg.org.uk/wp-content/uploads/2008/05/Travelling-with-Dementia.pdf

Making buildings accessible

The **Karolinska Institutet Sweden** has been working with people who have dementia to understand how **grocery shops and supermarkets** can be made accessible to them. Photos of different shop displays, features and layouts were used as the basis for discussion in focus groups. These discussions highlighted common problems with:

- illogical arrangements;
- overload of products, information and people;
- visual illusions (e.g. through the use of mirrors and glass doors or walls); and
- intrusive auditory stimuli

The researcher, Anna Brorsson[6], who has a background in Occupational Therapy, is now working to develop information to shopkeepers and food chains about how they can make their stores more Dementia Friendly. A short film and written information will be available at the homepage of the Swedish Agency for Participation from the start of 2017.

There are a number of practice examples in Europe and the United States in which cultural venues have been made accessible to people with dementia.

In the UK, the **West Yorkshire Playhouse, Leeds** has taken a number of steps towards becoming a 'Dementia Friendly Theatre'. These have included:

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[6] Based on email correspondence with the author in December 2016

- The Our Time group for people with dementia and their partners or supporters: these are creative sessions, using drama, art, poetry, song, movement and dance;
- Regular Dementia Friendly Performances which involve working with people with dementia and their supporters to adapt sound and lighting cues and stage action within the show itself where necessary; and pre-show creative sessions to prepare people for the show, either at the Playhouse or in the community.
- In-house dementia awareness training for 250 theatre staff over the past three years;
- Environmental audits of the venue commissioned from a group of people with dementia from another area. As a result of these, the Playhouse provides clear signage and visual markers, quiet spaces and additional trained staff and volunteers to support customers in the front of house space; and
- The theatre has produced guidance on Dementia Friendly Performances to pass their learning onto other venues and companies. This and other materials (such as radio broadcasts and a video about the initiative) can be downloaded from: https://www.wyp.org.uk/about/creative-engagement/older-people/dementia-friendly-performances/

The Community Development Manager was interviewed as part of this review and explained:

> 'This work grew out of our belief at the Playhouse that it is our responsibility to adapt and to make what we do accessible to everyone'.

Meet Me at the MoMA is a programme run by the Museum of Modern Art (MoMA) in **New York** to make the gallery accessible to people with dementia. Once a month the gallery is closed to the public and up to six small groups of around eight people with dementia and their supporters do a bespoke tour for 1.5 hours, which is led by a skilled educator. The group looks at and responds to around four pieces of artwork in the museum. The programme's formal and comprehensive evaluation (MoMA, 2014) demonstrates positive outcomes for participants, including their mood, self-esteem and relationships. Key success factors include the warm and interactive style of the educator, the structure and content of the tours, and the privacy and space which closing to the public affords.

'Coming to MoMA again, a place many had visited in the past but were reluctant to return to, was a welcome confirmation that not all valued parts of life have to be forfeited to Alzheimer's disease' (MoMA,2014, p.104).

A set of free resources, videos, guides for museums around how to set up such a programme are available to download (most are in Spanish as well as English) from: https://www.moma.org/meetme/resources/index#download

The model developed by Meet me at the MoMA was adopted by the **Van Abbe and Stedelijk museums in the Netherlands** in 2012 *('Unforgettable Van Abbe / Stedelijk').* With the support of the Gieskes-Strijbis Fundation, the programme will be expanded to ten other

museums in the Netherlands and Belgium. It is being evaluated by VU University Amsterdam. Further information is available at: https://vanabbemuseum.nl/en/mediation/special-guests/alzheimer-programme/

Making neighbourhoods and outdoor spaces accessible

There has been a series of research projects in the UK to identify what makes neighbourhoods accessible to people with dementia (Mitchell et al., 2003; Mitchell et al., 2007 and Blackman, 2003). These have identified six key principles of: familiarity, legibility, distinctiveness, accessibility, comfort and safety and seventeen accompanying recommendations related to these.

Recognising that urban areas tend to be modified slowly over time, the researchers have suggested a number of 'quick wins' or improvements that can be made outside of planned developments or adaptations. These include:

- Adding landmarks or distinctive features to assist wayfinding (especially at complex junctions);
- Making the entrances to public buildings obvious;
- Ensuring signage is clear and uncluttered; and
- Providing adequate street lighting, seating and hand rails.

(Mitchell in Pollock and Marshall, 2012)

Feedback from care-givers presented in the previous section highlights the importance of the police responding appropriately and empathetically where people with dementia have got lost, are unable to produce a ticket, have forgotten, or are unable to, pay. A number of the DFC coordinators interviewed for this review described work they have been doing to train police officers as part of their aim to improve the safety of their neighbourhoods for people with dementia. For example, in Dementia Friendly **Abbiategrasso in Northern Italy**, both the Police and care-givers requested that police officers receive training in dementia. These sessions have included basic awareness of dementia and tips and tools for communicating with people with dementia.

Assistive technology using **Global Positioning System (GPS) technology** can play a role in enabling people with dementia to get out and about independently, where this is done with the consent and full support of the person with dementia. Many tracking devices are now available on the open market, however the European Union Ambient Assisted Living Programme's Confidence project also developed and piloted (in **Austria, Romania and Switzerland)** smartphone-based technology to provide a 'virtual companion' to guide someone back to familiar places.

Making information accessible

Accessibility is not just a question of getting into a place and finding your way around; it is also about how you find out about it in the first place. In the UK, the Dementia Engagement and Empowerment Project (DEEP) has worked in partnership with people with dementia to produce a guide to writing Dementia Friendly information.

http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf

The Dementia Roadmap Wales is a web based platform providing high quality information about the dementia journey alongside local information about services, support groups and care pathways to support living well with dementia in Wales, with regionally specific resources. http://wales.dementiaroadmap.info

Safe places to meet and mix

A theme emerging from the group discussions with people with dementia is that people value safe places to meet and mix.

Smith and Gee 2016 argue that these should include outdoor as well as indoor spaces.

In **Cavan in the Republic of Ireland**, the local DFC initiative has been working to create a public reminiscence walking trail in the town. The walk has significant reminiscence features and talking points along the route. The intergenerational project to develop the trail involved students from the Cavan Institute. As the project lead, James Nevin explains:

> The reminiscence walk is not only for people living with dementia but can be used and enjoyed by other members of the family such as grandchildren, friends, associates and the wider community thus making it inclusive and an amenity for all generations to enjoy.

Some of the people with dementias and their carers who contributed to this review described how much they value being able to access mainstream social facilities, like sports clubs, pubs, bars and restaurants.

Several DFC initiatives in the UK hold relaxed drop-in sessions in local pubs. Peter Smith who runs several weekly pub-based sessions for people with dementia in Yorkshire, England told us:

> Lots of businesses say 'we can't change the physical environment!' and I say, 'no but it's more important to change the people! And you can do that'. I mean this pub doesn't have a fully accessible toilet. But the thing that puts people off using pubs is that carers are a bit embarrassed in case the person with dementia spills a drink or

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something. So it's about being made to feel welcome… if someone comes in here and goes to buy a drink but then can't find their money, the publican just makes a note – they don't make a fuss – they know they can ask for it another time.

Men's Sheds

Older men, especially those with dementia, can be at particular risk of social isolation. Community-based social groups tend to be dominated by and geared towards older women, and there is some evidence that men tend to prefer activities that have a practical outcome (Milligan, 2015). The Men's Sheds movement has been developed to create community spaces where older men can come together to work on practical projects. Milligan's (2015) evaluation of three shed projects for Age UK found that those in the early stages of dementia were able to 'make a real contribution' and thereby 'counter the frustration' of their condition through participating in Men's Sheds. However, the evaluation also highlights the support needs of these individuals and the occasional tensions in relation to their participation within the Sheds.

To test out how men with early-stage dementia and/or those caring for people with dementia could best be supported to access mainstream Men's Sheds, Alzheimer's Australia New South Wales commissioned and evaluated the 'Every Bloke Needs a Shed' project between 2011 and 2013. Alzheimer's Australia offered bus tours of local sheds to give men affected by dementia a taster of the different projects. They employed a link officer to support the men and their partners and to provide advice and education on dementia to others attending the sheds. The evaluation demonstrated the success and impact of this approach: a key theme from interviews with people with dementia and their spouses was the importance of the shed being a place where they could 'go to relax and get away from dementia' and where they can 'feel normal' (Abbato, 2013, p.18)

As a result of the learning from the pilot, Alzheimer's Australia has produced Your Shed and Dementia: A Manual https://www.fightdementia.org.au/about-dementia/resources/mens-shed-manual This guide is aimed at members and leaders of Sheds who want to improve their knowledge about dementia, and learn how to communicate better and provide practical assistance to Shed members who have or develop dementia.

1.8 Networks: Partnership structures

Dementia Alliances, Germany

The Federal Government in Germany is working to promote local 'Dementia Alliances', of which there are now around five hundred. The lead civil servant for this programme explained to us:

> We don't use the literal 'translation' of 'Dementia Friendly Communities' here: 'Dementia Alliances' is a better way for us to describe this in German; it also stresses that we are seeking to be united with people with dementia […] We want to support

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local Dementia Alliances so that they can work with and involve people with dementia in determining what they need locally […] the work of local Dementia Alliances has covered many different aspects of community life including sport, cultural activity, musical activity as well as the very 'ordinary' day to day aspects of life such as going to shops, using public transport and public services.

A spokesperson from Demenz Support Stuttgart added to this vision:

In essence we want to bring together and network people in Germany from a wide range of backgrounds, professional backgrounds linked to dementia and others from business and the wider community who don't have professional links to dementia.

Dementia Action Alliances, England

A national Dementia Action Alliance was established in England in 2010. The national group provides resources and support to nearly 300 local Dementia Action Alliances across the country. These partnerships bring together regional and local members to improve the lives of people with dementia in their area. They are seen as the local vehicle to develop DFCs, and can be established at any level, be it a village, city, county or even a region. They can overlap geographically and member organisations are encouraged to participate in more than one.

Heward (2016) studied the experiences of four part-time project workers trying to set up DFCs in seven localities in Southern England over a year. The research found that, although informal conversations between the coordinator and different local organisations can be effective in securing engagement, this is very time consuming and places too much emphasis on the coordinator, who then becomes the sole conduit for all of the local connections. In a Dementia Action Alliance, members build direct relationships with each other and, crucially, share responsibility for different work streams. Heward concludes that: 'Establishing Dementia Action Alliances provided a framework and appeared to be significant in ensuring the sustainability of work beyond the funding of the project.' (p.7).

We interviewed a number of people who are involved in Dementia Action Alliances in England for this review. Key success factors highlighted in these interviews included:

- The enthusiasm and vision of its members: 'a vibrant group of people driving it forwards – it's about a call to action': often the members of these groups are people who have had family experience of dementia;
- Having a 'hub': In Norfolk, DFCs were largely built with dementia cafes as their starting and focal point, which made it easier to secure the views and participation of people with dementia and their supporters, who should be involved throughout;
- Local alliances can be a good exchange point for information and resources. For example, London Fire Service explained that they are part of the pan-London Dementia Alliance group, but that their borough commanders also attend local dementia alliances where they exist in

individual London boroughs: this has resulted in some fire stations being used as local community hubs where groups can meet;

- Having a paid coordinator who can provide administrative support and follow up on actions can make a big difference to the impact and sustainability of alliances (an issue we explore further in the following section); and

- Getting the right balance between 'top-down' and 'bottom-up': being part of a county or regional alliance can be hugely beneficial in terms of influencing change at a more strategic level (and avoiding the need for county or regional organisations to attend lots of different meetings); however, it is crucial that local alliances have autonomy to identify their own priorities and develop their own activities, based on the barriers identified by local citizens.

1.9 Networks: Engaging and securing broad partnerships

Løten, Norway

Nasjonalforeningen for folkehelsen describe how the size of the place, combined with existing networks, has supported the effective development of a DFC initiative in Løten. Løten is a town with a population of just over 7000 people, in the South West of Norway.

> In Løten, the whole community has come together […] There seems to be a real pride in knowing they can give a better service to everyone, including people with dementia. If you visit the little town, you notice that there are DFC stickers in almost all the shops now.
>
> I think a key element here was that, at the start, they held a well-publicised open meeting – this included members of the general public, businesses, local politicians, people with dementia and caregivers from the local community. The focus of this meeting was very much on 'How can we all contribute to becoming a more Dementia Friendly Community?' So everyone felt a part of it.
>
> It helped, I think, that there has already been a lot of positive work in the health sector in Løten. People with dementia living in the town had already started to meet in conversational support groups and there was a Dementia Coordinator working in the health sector, who already had the relationships and, to some extent, the remit to drive the work forward. So key networks were already in place in this small town'.

1.10 Networks: Engaging people with dementia

The Dementia Engagement and Empowerment Project (DEEP), UK

DEEP is a UK wide network of groups of people with dementia. There are over 80 groups across the UK, most of which are involved in some way in supporting the development of DFCs in their areas. Each group is independent - some are Alzheimer's Society Service User Review Panels (SURPs), most are supported by a range of organisations, with a very

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small number being self-contained. Some have developed specific strategic relationships with their local Dementia Action Alliance, for example:

- Liverpool Service User Reference Forum (SURF) has representatives on each of the local Dementia Action Alliance's sub committees;
- York Minds & Voices group took over the whole agenda at a recent York Dementia Action Alliance meeting; and
- EDUCATE in Stockport supported the local DFC pilot in Marple by setting up a drop-in at a local pub. It has used European Foundations' Initiative on Dementia funding to support similar initiatives in Bradford, Cardiff and Oldham.

Almost all of the DEEP groups are involved in activities that feed into the development of DFCs. This has included audits of buildings, public space and services, as mentioned in the section on Place (EDUCATE's audit of the West Yorkshire Playhouse; Friends Together's input into the refurbishment of their local shopping precinct). Others have been involved in awareness-raising. In the group discussion with the Redditch and Bromsgrove DEEP group, one member articulated the value of speaking with experience:

> If you have got it you understand it, where in the sense if you understand the difficulties and problems so that you are much more capable of suggesting to somebody else what might have worked for you or what we are hoping will work for all of us.
>
> (Member of Redditch Group, Group discussion).

Members of the group have worked with local authorities, police, educational establishments, transport providers, local politicians and businesses. For example, the FIT Group in Bradford are involved in encouraging local business to become Dementia Friendly:

> We usually ask each organisation for at least three actions and we always say that the first one of those is always about raising awareness amongst the staff because I don't know if I have got this right, but I think awareness amongst staff is the thing that makes the most difference.
>
> (Member of FIT group, Group discussion)

DEEP has produced guidelines for involving people with dementia in DFCs: http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Involving-people-with-dementia-in-Dementia-Friendly-Communities.pdf/

Local Government Association/ Innovations in Dementia (2015) also contains further resources on this topic.

Dementia Friendly Kiama, New South Wales, Australia

While there are numerous examples of people with dementia attending and speaking at local Dementia Action Alliance meetings, there is evidence that having a parallel process through which people with dementia can contribute their views can also work well.

In Kiama, New South Wales, an advisory group of people with dementia has been set up to run alongside the Dementia Action Alliance - this appears to have been particularly effective in providing input and leadership to the alliance and an effective voice for people with dementia:

> It has all been about empowering people with dementia to be actively and proactively leading this project and steering it so therefore it is not a bunch of professionals doing it for other people; it is people with dementia and their supporters leading the project.
>
> (Dementia Alliance member).

In the (as yet unpublished) evaluation of the Kiama DFC (Dementia Illawarra Shoalhaven, 2015) the involvement of people with dementia is clearly identified as a key element to success. The report also recognises the need to build the capacity of people with dementia, if they are to play this role confidently and effectively.

1.11 Networks: Alternative approaches to engaging people with dementia

Community Ambassadors, Wicklow, Ireland

In Wicklow, Ireland, the DFC initiative used some of the funding they received from Atlantic Philanthropies (via Alzheimer's Society Ireland) to support an existing Community Ambassadors scheme. The 'ambassadors' were already engaging with older people, including some living with dementia, and trying to connect them up with other services and groups. The funding for this project was threatened, but with funding and training from the local dementia alliance, the ambassadors were able to continue their outreach work and gather insights into the experiences of people with dementia living in local communities to feed into the work of the alliance.

1.12 Resources: What resources do DFCs need and where are they getting them from?

Lokale Alliance für Menschen mit Demenz

The Federal Government in Germany, through its Bundesministerin für Familie, Senioren, Frauen und Jugend, has put in place a comprehensive programme to support local alliances for people with dementia (Lokale Allianzen für Menschen mit Demenz) and specifically to support these alliances to involve people living with dementia in determining what they want and need that will help to foster local DFCs.

It is intended that the work of dementia alliances will help break down the taboo associated with dementia and do this through a very wide range of local initiatives that mean that people living with dementia have a better quality of life through continuing to participate in leisure, social, cultural activity as well as finding day to day life easier.

Whilst the Government recognises that funding of 10,000 Euros over 2 years for each alliance is a relatively modest level of investment, it aims to provide an initial incentive and some practical assistance to establish local alliances.

This programme has also been intended to raise the political awareness of dementia so that both national, regional and local politicians see dementia as an important issue that they need to understand and be engaged with: 'We are not there yet in Germany in terms of creating Dementia Friendly Communities but we have made a start'.

Further information at: www.lokale-allianzen.de

Creating better lives for people affected by dementia in Scotland: strategic leadership and support

Dementia has become a national priority in Scotland. The Life Changes Trust is a charity that has developed an important role in this national context, not just as a funder using part of a £50 million endowment from the Big Lottery Fund, but also as a strategic leader.
The Trust uses its resources, of which its leadership role is a part, to work with others who share the aim of creating better lives for those affected by dementia.

The Trust sees its leadership role as, in part, being about working with and influencing Government and other statutory sector organisations, such as local councils and health services, to support a 'bottom up' vision of the development of DFCs.

Putting this into practice, the Trust uses its financial resources to support local groups, communities and partnerships where there is a commitment to an approach that is led by people affected by dementia and their families and supporters.

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Further information: www.lifechangestrust.org.uk

The Alzheimer's Society, (England): Dementia Friendly Communities Recognition process

The recognition process is designed to enable communities to be publicly recognised for their work towards becoming Dementia Friendly. The foundation stage of the process was built on seven criteria which were developed around what is important to people affected by dementia and their carers and consists of six-month and annual reporting requirements.

More detail on the process and the criteria used by the Alzheimer's Society can be found at: https://www.alzheimers.org.uk/downloads/file/2886/foundation_criteria_for_the_recognition _process

With an original target of 20 communities by March 2015, the process currently has over 200 registered communities working to become Dementia Friendly.

Interviewees from several local initiatives that are registered with the Alzheimer's Society told us that they valued the opportunities which this structure offered to connect with and learn from other projects, through their regional coordinator. Some found the reporting a useful opportunity to reflect on progress and identify outstanding actions.

Some Dementia Friendly initiatives in England have decided not to register with the recognition process. For example, the coordinator at Dementia Friendly Rothwell, despite having close links to his local branch of the Alzheimer's Society said: '[…] frankly we just wanted to get on with it, we didn't want a load of red tape [bureaucracy]'.

1.13 Resources: Monitoring and Evaluation

Alzheimer's Society Ireland developed a monitoring tool for its DFC pilots project. This includes 14 indicators attached to the four key priorities against which project applicants were assessed, i.e.:

- Promote the involvement of people with dementia and their families;
- Work in partnership with the community;
- Actions and outcomes to develop a DFC;
- Ensure evaluation, sustainability and dissemination of learning

This approach aimed to encourage flexible and locally specific evidence of process learning from projects; however, the coordinator reported that projects – many of which were being led by community volunteers – needed a lot of support to present their evidence in relation to each indicator.

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Dementia Friendly America has developed a series of matrices and worksheets for gathering the views of stakeholders about local priorities for activity and a method for collating these systematically and rigorously by plotting questionnaire responses against a graph. This approach could allow for follow-up measurements against baseline data, but will depend on the time, skills and willingness of those on the frontline to apply a highly structured approach. See http://www.dfamerica.org/toolkit/

APPENDIX 2

Research Team at Imogen Blood & Associates

Imogen Blood and Associates (www.imogenblood.co.uk) work with governments and services to make services and policies fairer and better.

Team members included the following:

Imogen Blood BA (Oxon), MA, Diploma of Social Work
Role in the Project: Project Lead

Steve Milton, Co-Director of Innovations in Dementia (IiD)
Project Role: Research Associate (as part of Innovations in Dementia partnership)

Ian Copeman BSc (Hons) MSc, Project Role: Research Associate

Shelly Dulson BA (Hons), IBA Business Support, Project role: Business Support and Research Assistance

Shani Blumenfeld MA, Project Role: Research Assistant

Jenny Pannell BA (Hons), MSc, FCI, Project Role: Research Associate:

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APPENDIX 3

Additional measures to employ during the testing phase of Workpackage 7 and to measure future impact assessment

Comprehensive set of potential/expected benefits	Category[2]	Broad area of impact	Types of measure	Brief description	Data source	Q1.1. Do you consider this is a suitable measure for WP7?	Q1.2.Do you consider this measure could be included in the WP7 pilot testing?
Concept of the Dementia Friendly Community used in a national policy, plan, program or project on the mental health, integrated care, chronicity.	Type of problem/knowledge addressed.	Research-related impacts.	QUANT	Number of strategic documents such as national plans, strategic programmee documents, guidelines and papers using Dementia Friendly	A set of bibliographic databases available on the Internet or requested to key stakeholders by survey.	Yes	Yes

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				Communities in their title or executive summary			
Increase in responsiveness/ public interest in toolkit of Dementia Friendly Community	Type of problem/knowledge addressed.	Research-related impacts.	QUANT	Toolkit downloads. Adapted toolkits to various societal and geographical areas across MS download.D7.1-Evidence-report downloads.	JA DEM 2 website. 7·1. Evidence Report. 7.2. Testing Report	Yes	Yes
Information on how to implement solutions related to Dementia Friendly Communities.	Type of problem/knowledge addressed.	Research-related impacts.	QUANT	D7.2.-Testing-report downloads.	JA DEM 2 website. 7.2. Testing Report	Yes	Yes

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New research topics in national strategic research founding call for topics related to Dementia Friendly Communities	Type of problem/knowledge addressed.	Research-related impacts.	QUANT	Number of national research funding call for topics related to Dementia Friendly Communities	Survey online	Yes	Yes
Impact of the WP7 on Dementia Friendly Communities based on publications (Dissemination).	Publications and papers.	Research-related impacts.	QUANT	Number of publications in scientific journals of WP7 on Dementia Friendly Communities	On the Internet. Specific query.	Yes	Yes
Impact of the WP7 on Dementia Friendly Communities based on technical reports, project reports, position statements (Dissemination).	Publications and papers.	Research-related impacts.	QUANT	Number of technical reports, project reports, position statements of WP7 on Dementia Friendly Communities.	On the Internet. Specific query.	Yes	Yes

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Impact of the WP7 on Dementia Friendly Communities based on citations of research publications by other researchers or stakeholders	Publications and papers.	Research-related impacts.	QUANT	Number of citations on SFC-WP7 on Dementia Friendly Communities in other publications.	On the Internet. Specific query.	Yes	Yes
Developing and maintaining collaborations between researchers, policy-makers and other users or institutes specifically for WP7 on Dementia Friendly Communities.	Research networks and user involvement.	Research-related impacts.	QUANT	Number of persons included in the contact list of WP7 that have contributed to some extent to either the Evidence, Testing, Dissemination or Evaluation phases	Survey online. Or List of stakeholders mentioned in acknowledgments of WP7 products	Yes	Yes

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Expanding linkages for multidisciplinary and cross-sectoral (health and social) research focused on the Dementia Friendly Communities area of interest.	Research system management.	Research-related impacts.	QUANT	Number of research projects with public funding (national or European) on the field of Dementia Friendly Communities in which there is involvement of the health and social sector.	Review related websites.	Yes	Yes
Overall researchers & collaborators satisfaction with Dementia Friendly Communities work package.	Research system management.	Research-related impacts.	QUANT	Level of satisfaction of researchers and collaborators involved in WP7 in relation to working conditions and areas of improvement.	Online survey.	Yes	Yes

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| To inform and influence of WP7 on Dementia Friendly Communities in policy and strategic planning at national, European, or international level. | Level of policy-making. | Policy impacts. | QUALI | Documented impact of WP7 on Dementia Friendly Communities area's findings on policy-making. Questions about the type of policy influenced by WP7 findings, particular types of policy institutions, nature of the policy influence etc. | Online survey or focus groups to national politicians, health services administrators and managers/directors, representatives of local, national and international professionals groups, NGOs and business leaders. | Yes | Yes |

Redefining/wider influence leading to changes or transformation of accepted beliefs or practices at local, national, European or international level in the field of Dementia Friendly Communities.	Level of policy-making.	Policy impacts.	QUALI	Documented impact of WP7 on Dementia Friendly Communities area's findings on policy-making. Questions about the type of changes, transformations achieved in this field.	Online survey or focus groups to national politicians, health services administrators and managers/directors, representatives of local, national and international professionals groups, NGOs and business leaders.	Yes	Yes
To inform and influence policy at national, European, or international level in the field of Dementia Friendly Communities.	Policy networks.	Policy impacts.	QUANT	Number of policy networks in which one of the WP7 members has participated or has informed.	On the Internet. Specific query or review related websites.	Yes	Yes

Evidence of benefits of interventions related to Dementia Friendly Communities	Evidence-based practice	Service impacts and Societal impacts.	QUAL	List of best practice models related to Dementia Friendly Communities that have shown some kind of benefits to improve lives of people living with dementia and their caregivers or other kind of evidences of benefits	In WP7 reports in Evidence and Testing Phase/ in future assessments of pilots or best practice models identified	Yes	Yes
Adherence to WP7 on Dementia Friendly Communities best practices and recommendations (active support).	**Evidence-based practice; Health Status; ICHOM (Clinical Status).**	Service impacts and Societal impacts.	QUANT	Hospital admissions (as a proxy of the clinical status). It would be expected to see less hospital admissions (avoidable) in	Administrative data.	Yes	Yes

				regions with more Dementia Friendly Communities			
Adherence to WP7 on Dementia Friendly Communities best practices and recommendations (active support).	**Societal capital and empowerment; ICHOM (Carer).**	Societal impacts.	QUANT or QUAL	Carer Quality of Life (proxy). It would be expected to show higher scores of Quality of Life and lower Burn-out in dementia friendly communities programmes or sites	Caregiver reported survey; online focus groups to caregivers and stakeholders involved in dementia friendly communities networks	Yes	Yes

Adoption of WP7 on Dementia Friendly Communities best practices and recommendations by health and social service providers.	Evidence-based practice.	Service impacts.	QUANT or QUAL	Documented adoptions "Dementia friendly" community approach in member states, Dementia friendly-health centres in member states or Dementia Friendly programmes; Number of open centres for older people?; Number of Dementia friendly-communities in member states.	Online survey or focus groups to national politicians, health services administrators and managers/directors, representatives of local, national and international professionals groups, NGOs and business leaders.	Yes	Yes
Higher accessibility of health and social services related to WP7 on Dementia	Quality of care (health and social sectors).	Service impacts.	QUALI	Questions about accessibility of the best	Online survey.	Yes	Yes

Friendly Communities area's interest.				practice model of a community "Dementia friendly" in member states.			
Positive changes in health and/or social systems in terms of efficacy, effectiveness, efficiency of Dementia Friendly Communities to improve the life of people living with dementia and caregivers	NEW SUBDOMAIN	Service impacts. Societal impacts	QUALI	Documented evidences or list of perceived changes collected from key stakeholders.	D.7.1-Evidence-report; D.7.2 Testing report. Online survey or focus groups to national politicians, health services administrators and managers/ directors, representatives of local, national and international professionals groups, NGOs and business leaders.	Yes	Yes
Less stigmatizing attitude against mental illness.	**Knowledge, attitudes and behaviour; social capital and empowerment;**	Societal impacts.	QUANT	**Number of Dementia friends or dementia friendly groups (as a**	Review related websites or online survey.	Yes	Yes

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	Specific WP7 benefits/ impacts.			**proxy of civic engagement).**			
More knowledge about the factors (key facilitators or elements of society to facilitate the inclusion and participation) defines a community or sections of communities or an environment as a "Dementia Friendly".	Knowledge, attitudes and behaviour.	Societal impacts.	QUANT	Number of leaflets on issues such as power of attorney downloads from the JA DEM website and partners involved.	JA DEM 2 website and review related websites.	Yes	Yes

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Improvements in health status by contributing to interventions (Dementia Friendly Communities) that reduce morbidity, mortality and disability and promote health as well as by developing methods to measure and monitor health status.	**Health status; ICHOM (Clinical status).**	Societal impacts.	QUANT	Overall survival of people with dementia	Administrative data (e.g. death registry)	Yes	Yes
More knowledge about the factors (key facilitators or elements of society to facilitate the inclusion and participation) defines a community or sections of communities as a	Equity and human rights.	Societal impacts.	QUANT	Number of national dementia patient organisations across member states.	Review related websites.	Yes	Yes

"Dementia Friendly".							
Adherence to WP7 on Dementia Friendly Communities best practices and recommendations (active support).	**Social capital and empowerment; ICHOM (Medication variables).**	Societal impacts.	QUANT	Antipsychotic drugs (rates of prescriptions of psychoactive medications in people with dementia. It is expected that communities more dementia friendly have lower rates of antipsychotic drugs	Clinical or administrative data.	Yes	Yes

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Less stigmatizing attitude against mental illness.	**Social capital and empowerment**	Societal impacts.	QUAL	Description of perceived benefits from society, people with dementia and careers and other k key stakeholders	Online survey or focus groups to national politicians, health services administrators and managers/directors, representatives of local, national and international professionals groups, NGOs and business leaders.	Yes	Yes
Empower people with dementia and their caregivers to remain independent for as long as possible (personal, family and social life).	**Social capital and empowerment; ICHOM (Symptoms, Functioning & QoL).**	Societal impacts.	QUANT/ QUALI	Daily living.	Online survey or focus groups to national politicians, health services administrators and managers/directors, representatives of local, national and international professionals groups, NGOs and business leaders.	Yes	Yes
Enable people living with dementia	**Sustainable development; ICHOM**	Societal impacts.	QUANT/ QUALI	Overall QoL and wellbeing.	patient/caregiver reported. Online	Yes	Yes

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to enjoy a better QoL.	**(Symptoms, Functioning & QoL).**					survey or focus groups		
Evidence of benefits in test sites of applying best practices in Dementia Friendly Communities	**Sustainable development, Knowledge, attitudes and behaviour; social capital and empowerment; among other perceived expected benefits**	Societal impacts. Service impacts	QUALI	Qualitative overall short-term impacts related to this global expected benefit from Joint Action Dementia	Online focus groups to national politicians, health services administrators and managers/ directors, representatives of local, national and international professionals	Yes	Yes
Evidence of adoption of evidence in member states not participating in the Joint Action DEM-2 in the field of Dementia Friendly Communities	**Level of policy-making. Sustainable development.**	Societal impacts. Service impacts. Policy making	QUALI	Qualitative overall short-term impacts related to this global expected benefit from Joint Action Dementia	Online groups to national politicians, health services administrators and managers/ directors, representatives of local, national and international professionals	Yes	Yes

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Evidence of stronger collaboration between member states in respect to dementia specifically in the field of Dementia Friendly Communities	Policy networks. Sustainable development	Policy impacts. Services impacts. Societal impacts	QUALI	Qualitative overall short-term impacts related to this global expected benefit from Joint Action Dementia	Online focus groups to national politicians, health services administrators and managers/ directors, representatives of local, national and international professionals	Yes	Yes
Evidence of continued EU prioritisation of dementia in the field of Dementia Friendly Communities	**Level of policy-making. Sustainable development.**	Policy impacts. Societal impacts	QUALI	Qualitative overall short-term impacts related to this global expected benefit from Joint Action Dementia	Online focus groups to national politicians, health services administrators and managers/ directors, representatives of local, national and international professionals	Yes	Yes

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APPENDIX 4
Technical Report

Evidence Review of Dementia Friendly Communities

European Union Joint Action on Dementia

20 January 2017

INTRODUCTION AND OVERVIEW

This technical report supports the findings of an evidence review conducted by Imogen Blood & Associates in partnership with Innovations in Dementia to inform Workpackage 7 of the EU Joint Action on Dementia, which is being led by the English Government (Department of Health). The evidence report aims to:

- Identify evidence-based examples of best practice in key aspects of promoting, nurturing and sustaining dementia friendly communities,
- provide a definition of DFCs,
- Identify the components of an effective DFC: arriving at a model demonstrating the key success factors of a DFC, synthesizing data from interviews, group discussions, online survey feedback, and key components of other existing models; and
- Develop a set of indicators to test the success of the forthcoming pilots within this Workpackage.

The evidence report is based on the following primary and secondary evidence:

- 82 reports and articles identified through a systematic search for international published and 'grey' literature;
- Three group discussions with people with dementia, including the European Working Group of People with Dementia and two groups within the Dementia Engagement and Empowerment Project network in England;
- 20 interviews with 25 participants with people involved in DFCs from a total of 10 countries across the EU, including two visits to DFC projects in the UK.
- An online survey, sent out to EU dementia leads and contacts, to which 57 responses were received.

The evidence report is structured around the 'four cornerstones' model, which has been used in the evaluation of several DFC initiatives in the UK. The four 'cornerstones' are: People, Place, Networks and Resources.

The review team were asked to draw on both secondary and primary data sources to develop a definition of DFCs and to describe the key components of a 'good' or 'effective' DFC. This was to be informed by a review of published and unpublished information from around the world, with a particular focus on evidence from EU countries.

The methodology for the review might best be described as a 'rapid evidence assessment', supplemented with primary data collection and stakeholder engagement. However, given the fairly limited amount of published research which specifically evaluates the effectiveness of DFCs, the team found that it needed to widen search terms, rather than make decisions about the exclusion of certain publications.

SELECTION OF METHODS

Conscious that we had only three months to complete the whole review, a 'scoping review' of the 'core' DFC literature specified in the brief was conducted at the outset. Having read this literature and run some initial searches for further literature on DFCs, a short 'scoping report was produced and shared with the Department of Health at start-up meeting. This document looked at the following topics/ questions:

i. What are the different approaches to defining 'Dementia Friendly Communities'?
ii. Principles of DFCs: what are the core principles according to these documents and what degree of congruence is there in relation to them?
iii. How are the different aspects of DFCs categorised in these documents?
iv. What forms of evidence have been collated and/or analysed in relation to DFCs?
v. Implications and questions to refine the methodology used and the final output

The initial searches confirmed that, although there was an emerging (English) literature on the effectiveness of DFCs, this was limited. This confirmed the importance of an EU-wide call for evidence, to identify evaluations which were unpublished and/or not available in English, to gather primary data about the state of DFC development in as many EU member states as possible, including examples of (albeit not yet evaluated) practice. The need to gather information in English as quickly as possible from as many EU countries as possible confirmed the importance of a flexible and multi-method approach, involving phone/ Skype interviews, an online survey and supplemented by email correspondence and Google searches for web-based information about DFC initiatives.

Ensuring that the views of people with dementia regarding effective DFCs were gathered by and informed the review was a priority for the team. Arranging to meet with existing groups of people with dementia was selected as both the quickest way of reaching a significant number of people within the timescales, and the best method ethically since people were already comfortable with facilitators and other members. Innovations in Dementia support the DEEP network of groups of people with dementia in the UK and workers from Innovations are already well-known to these groups so it was decided that Steve Milton and Damian Murphy of Innovations would conduct two group discussions with members of the York (North England) and Redditch (Midlands) DEEP groups.

It was the team's intention to return to these groups at the end of the review and share with them our proposed definition and model for verification, however, the opportunity arose to attend a meeting of the European Working Group of People with Dementia at the start of the report writing phase. A decision was made to share emerging findings with this group instead, given the clear advantage of gathering the views of people with dementia and their care-givers from a range of EU countries.

LIMITATIONS OF THE REVIEW

There are a number of limitations to this review:

- There was insufficient time and budget to review literature and information which was not in English language. To mitigate this as far as possible, we drew on the findings of the recent EFID review (Williamson 2016) (which had been able to translate primary and secondary data more proactively). Our online survey/ invitations to interview included the offer of translation/ interpretation and this was taken up on several occasions.

- Many of the countries contacted were at too early a stage in their DFC development to provide us with *any* information, let alone formal evaluations, though evaluations are planned or in process. Northern European countries were generally more advanced in terms of the development and evaluation of DFCs, therefore we recognise that the UK, Norway, the Netherlands and Germany are over-represented. The team sought to counter this with practice examples from Spain and Italy and with qualitative feedback from participants from a range of countries where the response to dementia is at a much earlier stage of development (e.g. Bulgaria, Portugal (Madeira), Greece, Czech Republic). These conversations provided a different frame of reference for the interpretation of evidence from elsewhere. This also meant that we looked further afield – to Australia, Japan and the US, where there is a well-established community of DFC practice.

- Given the time constraints of the project:
  - It was only possible to run the survey for 3 weeks, which may have restricted the response – the survey was mailed out to an email circulation list of those with an interest in DFCs drawn from across the EU, however, the team did not have any additional contact or role information so we were dependent on these contacts to act as 'gatekeepers', circulating the link to the survey/ completing it.

  - It was not possible to return to participants (including people with dementia) to iteratively test the model and definitions proposed; to mitigate this, we shared the draft report with those who contributed to the review, including circulating the easy read and full versions of the report with the groups of people with dementia we had consulted. We were not able to collect feedback systematically.

LITERATURE SEARCH

At the initial scoping stage, the team added to the list of existing 'core' literature provided in the specification by conducting Google searches using the terms 'Dementia Friendly Communities' with various added terms that included geographical areas, and/or 'evaluation', 'report'. The terms 'Dementia Supportive Communities' and 'Dementia-Capable Communities' were also searched. Since the focus was on identifying 'evidence-based' and 'effective' practice, the main focus was to find publications which presented the *findings of evaluations* of DFCs.

A number of definitions of DFCs were collated from the core literature and from Open Access academic papers and websites involved with DFC initiatives across the globe (eg Alzheimer's Disease International, Alzheimer's Europe, etc). These were reviewed to select four prominent but contrasting definitions on which online survey respondents were asked to feed back.

From the outset, the team used a spreadsheet to record the literature identified, its source and type.

At the next stage of the review, the team continued to use these search terms, and supplemented them with wider searches using the terms 'dementia' and 'community/ies'. Studies which looked at the effectiveness of medical or formal service provision to people with dementia living in community settings were excluded: the focus was on finding evidence related to how people with dementia experienced and accessed communities and how communities respond to and support those with dementia and their care-givers.

Manchester University Library Databases facilitated by the University's Research Information Management System, 'Pure', were searched for limited access publications. Through this system the team accessed several databases listed under the subject areas of:
- **Social Statistics and Social Change;**
- **Social Work; and**
- **Sociology.**

Within these subject areas the team were able to search databases for peer-reviewed journal publications, e-journals, articles and books. Key databases included:
- **Social Policy and Practice; and**
- **SAGE publications online.**

Via Manchester University Library, the team also accessed databases supported by EBSCOHost, (a delivery platform with extensive research content) including:
- **Social Sciences Full Text; and**
- **Sociology Source Ultimate**

In addition to searches through Manchester University Library, the team conducted searches via the following publically accessible search engines and databases:

- **'BASE'**: the academic search engine operated by Bielefeld University Library. It offers documents from more than 5,000 sources and supports indexed documents under Open Access;
- the UK's National Institute for Health and Care Excellence **(NICE) Evidence Search**, which provides access to selected and authoritative evidence in health, social care and public health;
- **Social Care Online**, which is the UK's largest database of information and research on all aspects of social care and social work;
- **Google**, whereby the team performed catch all searches across the world wide web; and
- **Google Scholar**, whereby the team identified abstracts to direct restricted access searches and to derive Open Access sources.

We grouped our searches into two categories:
- A direct relevance to the search term 'Dementia Friendly Community(ies)'
- A second search to source supporting evidence by using the simpler terms 'dementia' and 'community'.

In total the team collected 82 relevant documents which were made up of peer reviewed journal articles, evaluation and government reports, research updates and overviews, blogs, newspaper articles, books, tools, and synthesis and learning papers. The team also collected 2 papers via internal communications with participants and have listed organisational website sources where relevant.

In Table 1, which outlines identified documents below, the general term 'Manchester University Library' is used to describe our searches across several databases, of which key sources are listed above.

The team also searched for and collated relevant 'grey literature' looking for practice examples, especially those which had been evaluated. Typically, these searches were targeted following a mention of a practice example in an existing publication or an interview or survey response. For example, the team reviewed the EFID online collection of dementia-friendly community case studies across Europe[7] and the ADI Dementia Friendly Communities: Global Developments report (Alzheimer's Disease International 2016), conducting online searches (using Google) on those projects which mentioned 'evaluation'. The team found that many citations of evaluations were planned, in process, or could not be found.

Once identified, all documents were reviewed by the same researcher (Imogen Blood), who made notes on the spreadsheet under the following headings:

Evidence: references to/ description of formal evaluation, research questions, methods and sample size, limitations and gaps, evidence of impact

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[7] http://www.efid.info/eng/resources/dementia-friendly-community-case-studies/

Context: outline of the community/ies; organisation/ programme

Process learning: Key findings in relation to the effectiveness of structures, partnerships, approaches taken the DFC and how these evolved.

Although some critical appraisal was undertaken, at the time of the review, the evidence base in relation to DFCs was not of the nature, scale and stage of development to support a more structured comparative evaluation of studies. The process was therefore more akin to a synthesis of qualitative data.

Table 2: Documents Identified

No.	Type	Source	Topic/Key Feature	Reference
1.	Blog	Google	Reporting on building a DFC	Shafii, S. & Crockett, A. (2012) 'Building a dementia friendly community in Motherwell Town Centre— Our story so far', *Alzheimer Scotland*
2.	Book	Aktion Demenz	Comprehensive German perspective on DFCs	Gronemeyer, R., Kreutzner, G., and Rothe, V., (2015) *Im Leben bleiben: Unterwegs zu demenzfreundlichen Kommunen* (German only), Transcript Verlag, Bielefeld.
3.	Book	Manchester University Library	Good Practice	Rahman, S., (2015) *Living Better with Dementia: Good Practice and Innovation for the Future*, Jessica Kingsley Publishers, London
4.	Book	Google Scholar	Included Dementia Friendly pharmacy	Wegleitner, K., Heimerl, K., and Kellehear, A., (eds.) (2016) *Compassionate Communities: Case studies from Britain and Europe*, Routledge, London and New York.
5.	Evaluation Report	Social Care Online	Comprehensive evaluation and DFC project	IPC, (2015), *Evaluation of Hampshire Dementia Friendly Communities: Final Report*, Hampshire County Council.
6.	Evaluation Report	Google Scholar	Intergenerational exchange in Schools in support of DFCs	Atkinson, T., and Bray, J., (2013) *Dementia Awareness & Intergenerational Exchange in Schools: A Pioneer Project supporting Dementia Friendly Communities*, University of Worcester Institute of Health and Society.
7.	Evaluation Report	NICE Evidence Search	Detailed evaluation of Age UK's Dementia Friendly Programme	Kispeter, E., Alden, S., and Wigfield, A., (2015), *Age UK's Dementia Friendly Programme: Evaluation Report*, CIRCLE, University of Leeds

8.	Evaluation Report	Google	Evaluation in Scotland	Henderson, J., (2015) *Dementia Friendly Communities: Edinburgh City Initiatives 2014-2015,* A Stitch in Time, Edinburgh.
9.	Evaluation Report	Google	DFC pharmacy	Plunger, P., et al (2015) 'Dementia-friendly Community Pharmacy: findings from a Participatory project in Austria, Alpen Adria Universitāt
10.	Government Report UK	Google	Evaluation of peer support networks and advisors	Healthbridge (2013) *The National Evaluation of Peer Support Networks and Dementia Advisers in implementation of the National Dementia Strategy for England*, Department of Health, England.
11.	Journal Article	Google Scholar	Issues around stakeholder engagement	Heward, M., et al, (2016), 'Dementia-friendly communities: challenges and strategies for achieving stakeholder involvement', Health and Social Care in the community.
12.	Journal Article	Google Scholar	Definitions and concepts	Lin, Shih-Yin., and Lewis, F.M., (2015) 'Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future', *The Gerontological Society of America*, vol. 55, no. 2, pp. 237 - 244.
13.	Journal Article	Google Scholar	Evaluation of Alzheimer UK's Dementia Friends Programme with 1st year nursing graduates	Mitchell, G., et al (2016) 'Evaluation of "Dementia Friends" programme for undergraduate nursing students: Innovative practice', *Dementia.*
14.	Journal Article	Social Care Online	Descriptive - project overview in Wales	Chalk, A., (2014), 'Dementia RED (Respect Empathy Dignity): Collaborating to build dementia supportive communities in North Wales - reporting on a pilot project (innovative practice)', *Dementia*, 15(2), 2016, pp.257-262.
15.	Journal Article	BASE	Outside EU	Wright, T. (2014) 'Reconceptualising dementia friendly communities', *Diversity and Equality in Health and Care*, 11 (3). pp. 282-283. ISSN 2049-5471.

16.	Journal Article	Manchester University Library	Concept driven	Bartlett, R. (2016) 'Scanning the conceptual horizons of citizenship', *Dementia*, vol. 15(3), 453-461.
17.	Journal Article	Google	Workplace engagement with successful outcomes	Robertson, J., (2013) 'Side by Side: A workplace engagement program for people with younger onset dementia', in *Dementia*, vol. 12 no.5, pp. 666-674.
18.	Journal Article	Google	Seeks perspectives to develop a toolkit	Smith, K., (2016) *Developing a Dementia-Friendly Christchurch: Perspectives of People with Dementia*, Canterbury District Health Board and Age Concern Canterbury, New Zealand.
19.	Journal Article	Manchester University Library	Policy	Nedlund, A-C., and Nordh, J. (2015) 'Crafting citizen(ship) for people with dementia: How policy narratives at national level in Sweden informed politics of time from 1975 to 2013', *Journal of Ageing Studies*, 34 (2015) 123-133.
20.	Journal Article	Manchester University Library	Excellent refocus on PWD being at the centre of DFCs	Swaffer, K. (2014) 'Dementia: Stigma, Language, and Dementia-friendly', *Dementia* vol. 13(6), pp. 709-716.
21.	Journal Article	Google	Peer support, gender, inclusion of PWD	Milligan, C., et al (2015) 'Place and wellbeing: shedding light on activity interventions for older men', *Aging & Society*, 35, 2015, 124-149, Cambridge University Press.
22.	Journal Article	Manchester University Library	Citizenship	O'Connor, D. and Nedlund, A-C. (2016) 'Editorial Introduction: Special Issue on Citizenship and Dementia', *Dementia*, 2016, vol. 15(3), pp. 285-288.
23.	Journal Article	Manchester University Library	Relational aspects of place	Phillips, R., Evans, B. and Muirhead, S. (2015) 'Curiosity, place and wellbeing: encouraging place-specific curiosity as a way to wellbeing', *Environment and Planning* A 2015, volume 47, pp. 2339-2354.

24.	Journal Article	Manchester University Library	Quality of life	O'Rourke, H. M. et al, (2015) 'Factors that Affect Quality of Life from the Perspective of People with Dementia: A Meta-synthesis', *Journal of the American Geriatrics Society (JAGS)*, 63: 24-38.
25.	Journal Article	Manchester University Library	Environment and planning	Mitchell, L. et al, (2003) 'Making the outside world dementia-friendly: design issues and considerations', *Environment and Planning B: Planning and Design 2003*, volume 30, pp. 605-632.
26.	Journal Article	Manchester University Library	Environment and planning	Mitchell, L., Burton, E., and Raman, S. (2007) 'Dementia-friendly cities: designing intelligible neighbourhoods for life', *Journal of Urban Design*, 9:1, 89-101.
27.	Journal Article	Manchester University Library	Environment	Mapes, N. (2010) 'It's a walk in the park: exploring the benefits of green exercise and open spaces for people living with dementia', *Working with Older People*, Volume 14, Issue 4, December 2010.
28.	Journal Article	Manchester University Library	Holistic	Kane, R. A. and Cutler, L. J. (2015) 'Re-Imagining Long-Term Services and Supports: Towards Liveable Environments, Service Capacity, and Enhanced Community Integration, Choice, and Quality of Life for Seniors', *The Gerontologist*, vol. 55. no. 2, 286-295.
29.	Journal Article	Manchester University Library	Friendship and community	Hahmann, J. and Adams, R. G., (2015) 'Friendships and Community in Old Age', *The Gerontologist*, 2015, vol. 55, no. 3, pp. 506-508.
30.	Journal Article	Manchester University Library	Community awareness	Friedman, D.B, et al, (2016) 'Increasing Community Awareness about Alzheimer's Disease in Puerto Rico Through Coffee Shop Education and Social Media', *Journal of Community Health*, 2016, 41: 1006-1012.
31.	Journal Article	Manchester University Library	Overview of research based initiatives	Duffin, C. (2014) 'Dementia- friendly neighbourhoods', *Nursing Older People*, March 2014, volume 26, Number 2, pp. 16-17.

32.	Journal Article	Manchester University Library	Technology	Cutler, C., Hicks, B., and Innes, A. (2016) 'Does Digital Gaming Enable Healthy Aging for Community-Dwelling People with Dementia?', *Games and Culture*, vol. 11(1-2), pp. 104-129.
33.	Journal Article	Manchester University Library	Qualitative study	Brorsson, A. et al, (2016) 'Being a pedestrian with dementia: A qualitative study using photo documentation and focus group interviews', *Dementia*, vol. 15(5), pp.1124-1140.
34.	Journal Article	Manchester University Library	Housing	Bligh, J. (2016) 'A mainstream social housing response to dementia', *Working with Older People*, Vol. 20 Iss3 pp. 144-150.
35.	Journal Article	Manchester University Library	Accessibility of public space	Blackman, T. et al, (2003) 'The Accessibility of Public Spaces for People with Dementia: a new priority for the 'open city', *Disability and Society*, Vol. 18, No. 3, pp. 357-371.
36.	Journal Article	Manchester University Library	Japan and policy	Nakanishi, M. and Nakashima, T. (2014) 'Features of the Japanese national dementia strategy in comparison with international dementia policies: How should a national dementia policy interact with the public health-and-social care systems?' *Alzheimer's and Dementia*, 10, 468-476.
37.	Journal Article	Manchester University Library	Technology	Brittain, K., et al (2010) 'Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments', *Sociology of Health & Illness*, Vol. 32 No. 2, pp. 272-287.
38.	Journal Article	Manchester University Library	Place and citizenship	Clarke, C.L. & Bailey, C. (2016) 'Narrative citizenship, resilience and inclusion with dementia: On the inside or on the outside of physical and social places', *Dementia*, 2016, vol.15 (3), 434-452.
39.	Journal Article	Manchester University Library	Subjective experiences of PWD	Von Kutzleben, M., Schmid, W. Halek, M., Holle, B., Bartholomeyczik, S. (2012) 'A systematic review on the

				subjective experiences of persons with dementia', *Aging and Mental Health*, 16(3), 378-390.
40.	Journal Article	Manchester University Library	Enacting citizenship through walking together	Phinney, A, Kelson, E, Baumbusch, J, O'Connor, D, & Purves, B (2016) 'Walking in the neighbourhood: Performing social citizenship in dementia', *Dementia*, May 2016, v.15, no.3, 381-394.
41.	Journal Article	Manchester University Library	Arts and strengths-based approach	Depuis, SL, Kontos, P., Mitchell, G, Jonas-Simpson, C & Gray, J (2016) 'Re-claiming citizenship through the arts', *Dementia* 2016 v.15 (3) 358-380.
42.	Journal Article	Manchester University Library	Case study	'DF pharmacies a community based health promotion project' *BMJ Support Palliative Care* 2015;5:Suppl 1 A17.
43.	Journal Article	Manchester University Library	Workplace engagement	Robertson, J & Evans, D 2015, 'Evaluation of a workplace engagement project for people with younger onset dementia', *Journal of Clinical Nursing*, vol. 24, no. 15-16, pp. 2331-2339.
44.	Journal Article	Social Care Online	Outside EU	Wiersma, E. C., and Denton, A., (2013), 'From social network to safety net: Dementia-friendly communities in rural northern Ontario, Dementia, 0(0), 1-18.
45.	Overview Report	Social Care Online	Skills for Care funded programme of 12 pilot sites with 11 organisations, over a period of 12 months to support the development of DFCs	Henwood, M., (2015), *Living a Normal Life: Supporting the development of Dementia Friendly Communities*, Skills for Care, Leeds.
46.	Report	Social Care Online	Learning on engagement and empowerment	Seydak, E., et al, (2015), *Building a Dementia Friendly Community in Northern Ireland: Learning from the DEED Project in Derry*, Joseph Rowntree Foundation, York.
47.	Report	Social Care Online	Dementia Friendly Cities	Hare, P., and Dean, J., (2015), *How can we make our cities dementia friendly?,* Joseph Rowntree Foundation, York.

48.	Social Attitudes Survey Report	Social Care Online	Attitudes to Dementia in Scotland	Reid, S., Waterton, J., and Wild, A., (2015), *Attitudes to Dementia: Scottish Social Attitudes*, NatCen Social Research, London.
49.	Overview of Evaluation Progress Report	Google	Factors for developing DFCs	Easton, A., (2014), *Overview of the Dementia Friendly Communities Initiative*, The Alzheimer Society of Ireland, Republic of Ireland.
50.	Research Report	Alzheimer's Disease International	Comparison of DFCs and 'age-friendly communities'	Turner, N., and Morken, L., (2016) *Better Together: A Comparative Analysis of Age-Friendly and Dementia Friendly Communities*, AARP/WHO International Affairs, Washington DC.
51.	Report	NICE Evidence Search	Evaluation Report on DFCs in Oxfordshire, UK	IPC, (2014), *Oxford Dementia Challenge Group: Evaluation of Dementia Friendly Communities Project*, Oxford-Brookes University, Oxford.
52.	Overview of Progress Report	Google	Progress report of DFCs in Scotland	Life Changes Trust, (2015), *Dementia Friendly Communities: Report 1 – The First Six Months: April to September 2015, Life Changes Trust*, Glasgow.
53.	Workshop Report	BASE	Learning event on DFCs	Tippett, Joanne; How, Fraser; Wesslowski, Viktoria (2015) *Living well with dementia, Workshop at the North West Dementia Action Alliance Learning Event: building dementia friendly communities*, Ketso, Manchester.
54.	Report Findings	Google	National Survey	Alzheimer's Australia, (2014), *Living with Dementia in the Community: Challenges & opportunities: A report of National Survey Findings,* Alzheimer's Australia, Barton.
55.	Research Update (Overview)	Google	Identifying features of the physical and social service environments that help or hinder people with dementia	Dementia Illawarra Shoalhaven, (2015), *Dementia Friendly Kiama: Research Update*, University of Wollongong; Fight Dementia.org.au, Kiama Municipal Council, Kiama.

56.	Research Report	Google	Qualitative study using local hosts and forums	Orlando Health, Inc. and Carlin Rogers Consulting LLC, (2010), *Florida Dementia Friendly Transportation Research Project*, Florida Department of Elder Affairs, Florida.
57.	Report	Google	Summary of web searches worldwide for DFCs	Haggarty, M. (2013) *Dementia friendly communities worldwide: A summary of web searches*, Centre for Education and Research on Aging and Health (CERAH), Lakehead University, Thunder Bay.
58.	Review	Social Care Online	Review of progress and achievements of the Dementia Challenge	Henwood, M., Butler, T., and Pollard, K., (2015), *Slaying the Demon: The Dementia Challenge: Progress and Achievements*, University of the West of England, Bristol.
59.	Measurement Tool	Google	Quantitative measurement screening	Kaelen B., and Crey F., (2015) Dementieproof Meter 2015: Inventarisatie van Brabants Gemeentelijk Dementiebeleid, Programmaraad Zorgvernieuwing Psychogeriatrie, Tilburg.
60.	Yearbook	Alzheimer's Europe	Progress of DFCs across EU to date	Alzheimer Europe (2015), *Dementia in Europe Yearbook 2015: "Is Europe becoming more dementia friendly?" Examples of dementia friendly communities in: Austria, Belgium, Germany, Ireland, Netherlands, Norway and the UK*, Alzheimer Europe, Luxembourg.
61.	Updated dementia plan	Google	Projected plan to develop a dementia friendly Flanders	Vlaamse Regering, (2016) *Continuing to build a dementia-friendly Flanders together: Updated Dementia Plan for Flanders2016-2019*, Vlaamse Regering, Brussels.
62.	Poster	Google	Methods guide	Barclay, T., Barclay, M., & Mastery, O. (2015) *Building dementia -friendly communities: a collective action approach*, ACT on Alzheimer's, Minnesota.
63.	Evaluation Report	Google	Social isolation for men with early-stage dementia	Abbato, S., (2013) *Every Bloke Needs a Shed Project: Newcastle & Hunter Region,* Alzheimer's Australia, NSW.
64.	Evaluation Report	Google	Goals to advance the dementia capability of Minnesota	Paone, D., (2015) *Act on Alzheimer's Evaluation Report 2013-2015,* Act on Alzheimer's, Minnesota.

65.	Report	Google	Development guide	Alzheimer's Australia, (2014) *A Guide to Becoming a Dementia-Friendly Community,* Alzheimer's Australia, NSW.
66.	Report	Internal communications	Workshop report	Bruges and Aalbeke, (2015) *EFIS workshop: Exchange of practice and development of indicators to capture change,* EFID, Belgium.
67.	Publication	Google	Global developments on DFCs	Alzheimer's Disease International, (2016) *Dementia Friendly Communities: Global Developments,* Alzheimer's Disease International, London.
68.	Publication	Google	Key principles and resources guide	Alzheimer's Disease International, (2016) *Dementia Friendly Communities: Key principles,* Alzheimer's Disease International, London.
69.	Report	Google	Evidence from the perspective of people with dementia	Green, G., and Lakey, l., (2013) *Building dementia-friendly communities: A priority for everyone,* Alzheimer's Society, London.
70.	Annual Report	Google	Quality of life for older people with dementia	Kane, M., and Terry, G., (2015) *Dementia 2015: Aiming higher to transform lives,* Alzheimer's Society, London.
71.	Code of Practice	Google	Recognition of DFCs	Alzheimer's Society, (2015) *PAS 1365: 2015 Code of practice for the recognition of dementia-friendly communities in England,* British Standards Institution (BSI), London.
72.	Evaluation Report	Google	Identifying distinctive features of DFC Programme	Dean, J., Silversides, K., Crampton, J., and Wrigley, J., (2015) *Evaluation of the Bradford Dementia Friendly Communities Programme,* Joseph Rowntree Foundation, York.
73.	Evaluation report	Google	Identifying distinctive features of DFC programme	Dean, J., Silversides, K., Crampton, J., and Wrigley, J., (2015) *Evaluation of the York Dementia Friendly Communities Programme,* Joseph Rowntree Foundation, York.
74.	Report	Internal Communications	Learning from two pilot local authorities	Innovations in Dementia, (2012) *Developing dementia-friendly communities: Learning and guidance for local authorities,* Local Government Association, London.

75.	Report	Google	Mapping DFCs in Europe	Williamson, T., (2016) *Mapping dementia-friendly communities across Europe: A study commissioned by the European Foundations' initiative on dementia (EFID),* EFID, Brussels.
76.	Departmental Policy Commitment	Google	UK Government policy priorities on dementia	Department of Health England, (2015) *Prime Minister's Challenge on Dementia 2020,* Department of Health England, London.
77.	Departmental implementation plan	Google	UK government plan for implementing Prime Minister's Challenge on Dementia 2020	Department of Health England, (2016) *Prime Minister's Challenge on Dementia 2020: Implementation Plan,* Department of Health England, London.
78.	Proceedings from Roundtable	Google	Intellectual disability policy	Wilson, E., (2006) *Defining and measuring the outcomes of inclusive community for people with disability, their families and the communities with whom they engage,* La Trobe University, Melbourne.
79.	Devolved Government Publication	Google	Best practice guidance	The Scottish Government, (2007) *With Inclusion in Mind: The local authority's role in promoting wellbeing and social development: Mental Health (Care and Treatment)(Scotland) Act 2003 Sections 25-31,* The Scottish Government, Edinburgh.
80.	Grey Journalism	Google	Japan's approach to dementia	Yang, J., (2015) 'How Japan is training an entire country to help with dementia', *thestar.com,* Toronto Star Newspapers Ltd., Toronto [online] (Accessed 10/08/2017) https://www.thestar.com/news/world/2015/11/22/how-japan-is-training-an-entire-country-to-help-with-dementia.html
81.	Grey Journalism	Google	Feature on Bruges's approach to DFCs	Davies, R., (2015) 'Is Bruges the most dementia-friendly city?', *The Guardian*, Guardian News and Media Limited, London [online] https://www.theguardian.com/society/2015/apr/21/bruges-most-dementia-friendly-city (Accessed 10/08/2017)

| 82. | Grey Journalism | Google | Speech given at Alzheimer's Disease International of Singapore | Rees, G., (2015) 'Dementia Friendly Communities: Global Initiatives and Future Directions, *Dementia Alliance International,* Iowa [online] https://www.dementiaallianceinternational.org/dementia-friendly-communities-global-initiatives-and-future-directions-by-glenn-rees-am/ (Accessed 10/08/2017) |

The team also gathered details of a range of Toolkits to inform the next phase of the European Union Joint Action on Dementia Project from established DFC initiatives around the world. These are listed in Table 2 below:

Table 2: Toolkits

Title	Country	URL (Shortened)	Comments
ACT: Dementia Friendly Toolkit	Minnesota, USA	http://bit.ly/2cEa9lf	Good resource in relation to evaluation
Dementia Friendly America: Toolkit inventory	USA	http://bit.ly/2x3pWjc	Includes action for sectors
A Toolkit for Building Dementia-Friendly Communities. Wisconsin's Healthy Brain Initiative Project	Wisconsin, USA	http://bit.ly/2wPBlEa	Good example of process and sustainability (p.24)
Alzheimer Scotland: Action on Dementia: Dementia Friendly Toolkit	Scotland, UK	http://bit.ly/2w9I1Ql	Several resources are accessible: • a leaflet for shops and businesses • Environmental poster and audit tool • Charter of rights for people with dementia
Deep (Dementia Engagement and Empowerment Project)	UK	http://bit.ly/1PI1SKx	Includes a range of engagement guides and a booklet of 'Our Rights'
Local Government Association: Dementia friendly communities: Guidance for councils	UK	http://bit.ly/2uOuARv	Local Government Association (LGA) Guidelines
Innovations in Dementia (IiD): How to do an access audit	UK	http://bit.ly/2vCWNO0	How-to guide on conducting an audit to make buildings easier for people with dementia
Age UK: How to make your Age UK dementia friendly	UK	http://bit.ly/2v10MQV	How to make a local organisation working with older people dementia friendly
Alzheimer's Disease International: Dementia Friendly Communities: Key Principles	International	http://bit.ly/2wdRl4L	Key principles paper

Alzheimer's Disease International: Dementia Friendly Communities: Global Developments	International	http://bit.ly/2fJDfSq	Good for descriptions of how tools are being used
Alzheimer's Australia: Creating Dementia Friendly Communities: Community Toolkit	Australia	http://bit.ly/2weD9bA	- Includes good and simple ideas along with a template for action - Good checklists for environment, both indoor and outdoor, and for social interaction
Alzheimer's Australia New South Wales: A Guide to Becoming a Dementia friendly Community	NSW, Australia	http://bit.ly/2e4RjVe	Good resource on Strategy – Kotter 8 step change model
Alzheimer's Australia: Creating Dementia Friendly Communities Business Toolkit	Australia	http://bit.ly/2uIjYaC	Business Toolkit
Alzheimer's Australia: Creating Dementia Friendly Communities: A Toolkit for Local Government	Australia	http://bit.ly/2vD16sK	Good resource for sample surveys and templates
Is it Dementia: A resource for recognising the signs of dementia	Australia	http://bit.ly/2i4lY7j	Sector specific awareness resources
Alzheimer's Australia: CALD Dementia Resources for Families and Professionals	Australia	http://bit.ly/2uOMinG	Good resource for Black, Asian and Minority Ethnic Groups
Alzheimer's Australia: Your Shed and Dementia A Manual	Australia	http://bit.ly/2v1jcki	A manual on making the 'Men's Sheds' programme more accessible to people with dementia
Alzheimer's Australia WA: Dementia Friendly Communities Project: Creating a Dementia friendly WA	Western Australia	http://bit.ly/2wPUhSX	Good resource for how to set up an evaluation to include people with dementia
Alzheimer's Australia: A Practical Model for Local Governments, Civic	Australia	http://bit.ly/2uIn922	Guidelines for communities (aimed at local government and a good rationale for DFCs

Services and Community Organisations			and on alignment with age friendly work.
Dementia Enabling Environments	Australia	http://bit.ly/2fKs63Q	Good assessment tool for mapping journey to accomplish specific tasks – useful for events and public buildings
Dementia Action Alliance: Creating a local dementia action alliance	England, UK	http://bit.ly/2wPnZYq	Guidance for setting up a Dementia Action Alliance
Alzheimer's UK: A guide for MPs and councillors to create dementia-friendly communities in England	UK	http://bit.ly/2weuBl7	Guidance for local politicians
Alzheimer's UK: Becoming a dementia-friendly arts venue: A practical guide	UK	http://bit.ly/2wPBtn4	Aimed at arts venues
Alzheimer's UK: Creating a dementia friendly workplace	UK	http://bit.ly/2kPh76v	Creating a dementia friendly workplace
Alzheimer's UK: Dementia Friendly Technology	UK	http://bit.ly/2prBHwm	Technology charter
Alzheimer's UK: Making financial services more dementia friendly	UK	http://bit.ly/2weeiF6	Financial Services Charter
Alzheimer's UK: Guidance and tips for staff to help people with dementia	UK	http://bit.ly/2w9OmuX	Tips for customer facing staff
Alzheimer's UK: Creating a dementia-friendly generation	UK	http://bit.ly/2wPh9Cf	Creating a dementia friendly generation
Alzheimer's UK: Becoming a dementia-friendly retailer: A practical guide	UK	http://bit.ly/2fKtkfj	Retailers guide
Alzheimer's UK: How to become dementia friendly: Quick tips for organisations and businesses	UK	http://bit.ly/2ngBOgN	Tips for businesses and organisations
Dementia Enabling Environments	Australia	http://bit.ly/2fKs63Q	Comprehensive and clear guidance on accessibility
Public Health Agency of Canada: Age-friendly communities valuation guide	Canada	http://bit.ly/2w9BN2N	Age friendly indicator development: useful in planning evaluations

Using indicators to measure progress			
WHO: Measuring The Age-Friendliness of Cities A Guide to Using Core Indicators	International	http://bit.ly/2ncUm0d	Comprehensive guide to setting up evaluation processes
WHO: Check list of Essential Features of Age-friendly Cities	International	http://bit.ly/1FOWnPN	Checklist of age-friendly features
Belfast City Council: Age-Friendly Belfast	Northern Ireland	http://bit.ly/1swJWWl	Intergenerational Toolkit/leaflet
AARP: Evaluating Your Age-Friendly Community Program A Step-by-Step Guide	USA	http://bit.ly/2w0QTaw	A straightforward and accessible guide to evaluation of age-friendly initiatives
Swimming.org: Dementia Friendly Swimming	England	http://bit.ly/2uIlsln	- Resources that include training materials - Thorough access and audit guide for leisure centres - Marketing materials - Feedback forms - Planning Materials - Role-specific set of training outlines
Joseph Rowntree Foundation, Alzheimer's Society Northern Ireland and British Deaf Association: Dementia friendly communities: supported learning and outreach with the deaf community	UK	http://bit.ly/1Ykt6FL	Deafness and Dementia in relations to DFCs
Dementia Without Walls	UK	http://bit.ly/2uIwqr8	Resources on evaluation
West Yorkshire Playhouse: Guide to Dementia Friendly Performances	Yorkshire, UK	http://bit.ly/1sm2vyM	Dementia Friendly Performances
NHS England: Dementia Friendly Dentistry: Advice and guidance for the	UK	http://bit.ly/2vDxECK	Guidelines for dentists

primary dental care team: Dementia Toolkit			
Tunbridge Wells Museum & Art gallery: Dementia Toolkit	UK	http://bit.ly/1Rv3V4F	Guide for creating dementia friendly museums
The Alzheimer's Society of Ireland: Supporting people with dementia: A guide for retailers	Republic of Ireland	http://bit.ly/2wauQ1A	Retailers guide
Genio: Inclusion of People with Dementia in the Design of Services	Republic of Ireland	http://bit.ly/2uIZeQ5	Guide to involving people with dementia in service design
Dementia Elevator	Republic of Ireland	http://bit.ly/2uJkHbT	Sector specific awareness courses
Dementia Action Alliance: Guidance for businesses	England, UK	http://bit.ly/2wfoJYP	Factsheet for businesses
Dementia Action Alliance: Examples of Actions	England, UK	http://bit.ly/2vDG8Ki	List of actions by sector
Social Care Institute for Excellence (SCIE): Dementia – What it is and what it isn't	UK	http://bit.ly/2uPpS64	Open learning course
Social Care Institute for Excellence (SCIE):	UK	http://bit.ly/2vINB9j	Good resource concerning environments
How to become a dementia friendly practice	England, UK	http://bit.ly/2wfiSD5	Guidance for primary care staff

PRIMARY QUALITATIVE DATA COLLECTION FROM STAKEHOLDERS

Central to our methodology was to engage with people who are personally affected by dementia and the organisations that represent them. We did this in four ways (discussion groups, online survey, professional phone interviews and a meeting in Brussels of the European Working Group of People with Dementia).

Discussion groups with people with dementia in England

First, via Innovations in Dementia's connections to the DEEP network, we conducted two discussion groups, one in Bradford with the members of the 'Face It Together (FIT) group (here 6 people joined the discussion for approximately one hour), and the second in Redditch with the Redditch Friends Together group (7 members attended for a one-hour discussion).

To maintain consistency, we devised a topic guide that included the following questions/topic areas:

- What are your experiences in your local community: what is your biggest complaint?
- What does a truly DFC look like?
- How would it make you feel?
- What would help this happen?
- What would hinder this?

To thank our participants for their time, we made small 'thank you' payments.

All participants were able to offer informed consent and this was audio recorded in writing at the time of interview. The team discussed the feasibility of asking individuals to complete a monitoring questionnaire asking for demographic information, however it was decided that this would could be stressful and off-putting for individuals (who attend without the support of a care-giver). Furthermore, it was felt that, perhaps the most pertinent aspect of demographic profile, i.e. the degree of severity of a person's condition, would be almost impossible to assess in a meaningful and reliable way and risked medicalising the ethos of the group.

The discussions were audio recorded, written up as transcripts and analysed thematically under the 'cornerstone' themes of 'People', 'Place', 'Networks', 'Resources' and 'the involvement of people with dementia'.

CALL FOR EVIDENCE

Secondly, using a long list of contacts provided by the England Department of Health, we sent a mass mail-out to 71 European counterparts in 29 countries with a 'call for evidence and information request'. As well as using this avenue to collect primary information and data, this also provided the opportunity to directly engage those involved with initiatives. We initiated telephone interviews with a selection of those who responded to call.

A list of EU countries we attempted to contact and detail of progress / response is given below in Table 3:

Table 3: Countries Included

Country	Data Collection
Austria	Exchanged email contact but did not return for interview, included practice e.g. based on published evidence
Belgium	Did not respond to invite
Bosnia and Herzegovina	No contact available
Bulgaria	In-depth phone interview

Croatia	Did not respond to invite
Cyprus	Did not respond to invite
Czech Republic	Responded by email to say there were no initiatives in the Czech Republic at present, however they were represented at the EWGPWD and interviewed
Denmark	Did not respond to invite
Estonia	Did not respond to invite
Finland	Interviewed at the EWGPWD
France	Email response saying too early to collect data as initiatives at launch stages during the review
Germany	Conducted two in-depth telephone interviews and also interviewed at EWGPWD
Greece	Conducted an online focus group with three Greek participants
Hungary	Did not respond to invite
Ireland	Received 2% of our responses from the Republic of Ireland and conducted an in-depth interview, also interviewed at EWGPWD
Italy	Received a very late survey response (for which we extended our deadline to include), and conducted an in-depth interview
Latvia	Did not respond to invite
Liechtenstein	Did not respond to invite
Lithuania	No contact available
Luxembourg	Did not respond to invite
Malta	Did not respond to invite
Netherlands	Received 2% of survey responses from the Netherlands. The team tried to arrange an interview with a spokesman from the Netherland but no response was forthcoming, however the team received helpful and informative feedback on the report.

Norway	Received 22% of our survey responses from Norway, and conducted two in-depth telephone interviews, also interviewed at EWGPWD
Poland	Received 2% of survey responses from Poland
Portugal	Interviewed at the EWGPWD
Romania	No contact available
Scotland	Received many survey responses and conducted an in-depth phone interview; also interviewed at EWGPWD
Slovak Republic	Did not respond to invite
Slovenia	Did not respond to invite
Spain	Received 2% of our responses to the online survey and conducted an in-depth phone interview with two specialists using an interpreter
Sweden	Exchange email contact and information sharing, interviewed at EWGPWD and included practice example based on published evidence.
UK (England, Wales and Northern Ireland)	Received the majority of survey responses and around half of our interviews from the UK

PROFESSIONAL INTERVIEWS

We conducted 20 interviews with 25 participants consisting of 14 1-1 in-depth phone interviews lasting for up to one hour with the exception of an interview conducted in Spanish with an interpreter, which took over an hour. 3 group interviews via phone / Skype and 3 1-1 interviews in person. We conducted interviews during face-to-face visits with individuals who were based in the North of England and where this allowed us to meet face-to-face with people with dementia and their supporters. We visited:
- One individual living in a care home;
- A theatre which has been working to become dementia friendly, since this allowed us to meet a group of people with dementia and observe part of the regular creative session they attend, as well as interview the Community Development worker;

- A regular pub meeting of a 'grassroots' Dementia Friendly initiative, where we were able to speak informally to people with dementia and their caregivers as well as interview the voluntary coordinator before the session began.

These opportunities enable us to see some dementia friendly initiatives in action.

We developed a menu of questions to be used flexibly in the interviews, the purpose of which were:
- To identify and gather information on case studies;
- To understand some of the national differences (dementia infrastructure, culture, etc.) which might influence the opportunities and barriers for the development of DFCs;
- To identify what is needed from this evidence review, the forthcoming toolkit and pilots to support development of DFCs in this context?
- To explore how the concept of a DFC is understood and defined.

The menu of questions asked in the phone interviews included:
- What is a 'Dementia Friendly Community'? Do you feel there are differences of opinion/ ambiguities here?
- How would you describe the evidence base in relation to DFCs at present? Where are the gaps? Are you able to tell us about studies or reports in your country / organisation which we should include in our review? How do you know DFCs work?
- What are the key features of a good DFC from your perspective?
- What helps to build and maintain a DFC or accessible communities?
- What gets in the way?
- What difference should a good DFC make to those living within it: those affected by dementia, businesses, public services and community organisations?
- What is the gap that this report can fill in your view? What evidence is needed to help policy makers and people in communities and service providers launch, nurture sustain and promote DFCs (in your country)?
- Tell us about your good practice in relation to DFCs.

Researchers wrote up their interview notes and these were thematically analysed, using the headings of the 'cornerstones model' as nodes.

Table 4 below provides detail of interviewees:

Table 4: Professional Interviewees

Name	Role	Organisation	Country	Method
Shima Mehrabian	Member of Executive Board Neurologist, Bulgaria	Bulgarian Society of Dementia University Hospital Alexandrovska, Sofia	Bulgaria	1-1 phone interview

Gabriele Kreutzner	Information and Publicity Lead	Demenz Support Stuttgart gGmbH	Germany	1-1 phone interview
John Starr	Chair	Saffron Walden Dementia Action Alliance	England	1-1 phone interview
Petra Weritz-Hanf	Civil servant responsible for health in old age, help with dementia	Federal Ministry for Family Affairs, Senior Citizens, Women and Youth Federal Government	Germany	1-1 phone interview
Anna Buchanan	Director, People affected by dementia programme	Life Changes Trust	Scotland	1-1 phone interview
Avril Easton	Project Leader - Dementia Friendly Communities	Alzheimer's Society Ireland	Ireland	1-1 phone interview
Ioanna Petroulia	Centre for Health Services Research	Department of Hygiene and Epidemiology Medical School University of Athens	Greece	Group discussion via Skype
Antonios Politis	Associate Professor, Geriatric Psychiatry	National and Kapodistrian University of Athens	Greece	
Antonis Mougias	Psychiatrist

President | Nestor Psychogeriatric Association (specialist dementia clinic), Athens Association of Caregivers for Patients with Alzheimer's Disease and Related Disorders | Greece | |
Kari Midtbø Kristiansen	Executive manager	Norwegian National Advisory Unit on Ageing and Health	Norway	1-1 phone interview
Randi Kiil	Head of Comms	Norwegian Health Association (Nasjonalforeningen for folkehelsen)	Norway	Group interview via phone
Ingrid Rise Fry	Dementia Friendly Communities Programme Manager	Norwegian Health Association (Nasjonalforeningen for folkehelsen)	Norway	
Assumpció González Mestre	Lead for Patient Expert Group of Catalonia	Strategic Programme for Prevention and Care in	Spain	Group interview via phone

		Chronicity Department of Health of Catalonia		
Paloma Amil	Member of Patient Expert Group of Catalonia	Strategic Programme for Prevention and Care in Chronicity Department of Health of Catalonia	Catalonia (Spain)	
Esther Sánchez	Member of Patient Expert Group of Catalonia	Strategic Programme for Prevention and Care in Chronicity Department of Health of Catalonia	Catalonia (Spain)	
Mario Possenti	Association Coordinator	Federazione Alzheimer Italia	Italy	1-1 phone interview
Ana Diaz	Project Officer	Alzheimer Europe	Luxembourg	1-1 phone interview
Ann Johnson	Person living with dementia and retired nurse educator	UK Prime Minister's Champions Group for Dementia	England	1-1 interview in person
Becca Reed	Community Engagement Administrator, Dementia Friends Team	Alzheimer's Society	England	1-1 phone interview
Emma Fraser	Senior Development Officer Community Safety Policy and Projects	London Fire Service	England	1-1 phone interview
Jo Hughes	Project Coordinator, Side-by-side	Alzheimer's Society, Worcestershire	England	1-1 phone interview
Tracy Sneider	Dementia Friendly Communities Project Officer	Kent County Council	England	1-1 phone interview
Nicky Taylor	Community Development Manager	West Yorkshire Playhouse	England	1-1 interview in person
Peter Smith	Voluntary coordinator (and former family care-giver)	Dementia Friendly Rothwell, Leeds	England	1-1 interview in person and informal conversations with people with dementia and care-givers attending session

| Shibley Rahman	Author and Retired Medic	Independent	England	1-1 phone interview

ONLINE SURVEY

Thirdly, we devised an online survey using Survey Monkey, which was aimed at capturing the views of a broad range of DFC stakeholders including people with dementia and those with other lived experience. Participants were offered the opportunity to fill in the survey in their own language. Using our contact list from the 'call for evidence' and any new contacts made from the responses, we sent out a second mass mail to invite European counterparts to take part in the survey and to distribute it amongst their networks. Our research assistant in charge of the survey analysed the findings thematically to inform the final report.

Our online survey provided 57 responses in total and respondents were asked the following:
- What helps people with dementia to take part in everyday life in your local area?
- Which people or organisations (can) help this to happen?
- What stops people with dementia from taking part in everyday life in your local area?
- Which people or organisations can remove these barriers?
- What does the term 'Dementia Friendly Community' mean to you?
- What they thought about the strengths and weaknesses of four alternative definitions supplied (definitions listed below):
  - 1: 'A dementia friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them';
  - 2: 'A dementia friendly community is one that enables people with dementia to: i) Find their way round and be safe; ii) Access the local facilities that they are used to and where they are known (such as banks, shops, cafes, cinemas and post offices); and iii) Maintain their social networks so they feel they continue to belong';
  - 3: 'A dementia friendly community is a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value'; and
  - 4: 'Dementia friendly communities are geographic areas where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia friendly community people are aware of and understand dementia, and people with dementia feel included and involved, and have choice and control over their day-today lives. A dementia friendly community is made up of individuals, businesses, organisations, services, and faith communities that support the needs of people with dementia'.
- How have you been involved in DFCs?
- Please tell us which country you are based in.
- How, in your view, can we tell if DFC initiatives are working?

- We are currently looking for examples which highlight what works in getting DFCs started, publicising them, and keeping them going. We want to include examples from different countries and contexts. If you would like to suggest an example, please give us contact details or a link so we can find out more.

The survey asked people to say whether or not they had lived experience of dementia for monitoring purposes and asked how respondents were involved with DFCs. Details of the involvement are produced in the chart below:

Q10 **How have you been involved in dementia friendly communities?**

Answered: 45   Skipped: 5
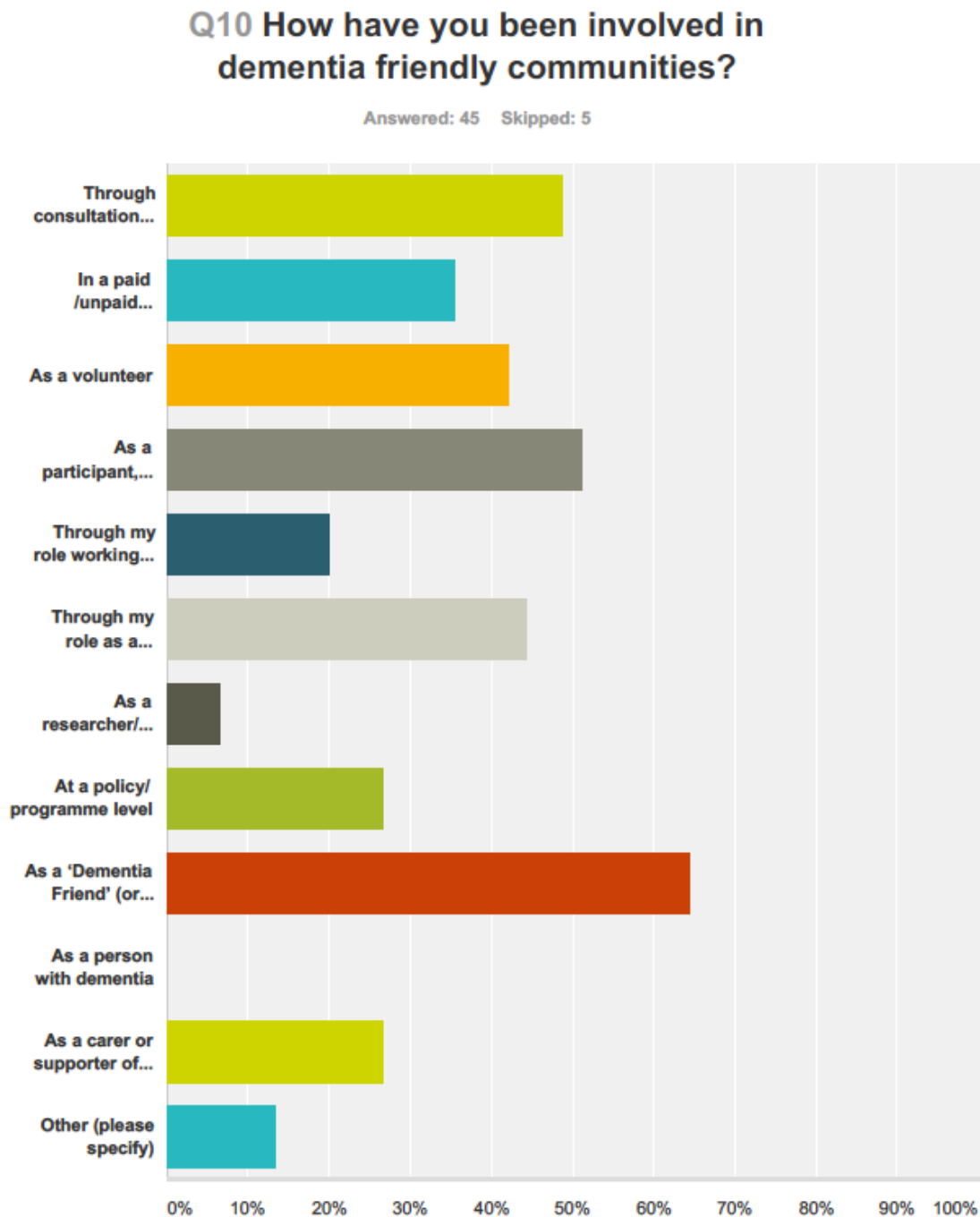
The survey link was sent out to 26 countries via a list of email addresses provided by the England Department of Health, however 8 of those email addresses did not contain information on their country of origin. Organisations and roles of contacts were not provided. A representative table of countries receiving the survey is given in Table 5 below:

Table 5: Countries receiving online survey

Country	# Contacts distributed to
Austria	1
Belgium	1
Croatia	1
Cyprus	2
Czech Republic	1
Denmark	1
Estonia	1
Finland	1
France	3
Germany	2
Greece	3
Hungary	2
Ireland	4
Italy	6
Latvia	2
Liechtenstein	2
Luxembourg	3
Malta	1
Netherlands	1
Norway	6
Poland	2
Portugal	1
Scotland	2
Slovak Republic	2

Slovenia	1
Spain	3
UK (England, Wales and Northern Ireland)	1

Although the survey received 57 responses, it is not possible to describe this as a response rate as contacts were asked to distribute the survey throughout their networks. The survey was also anonymous.

FOCUS GROUP WITH EUROPEAN WORKING GROUP OF PEOPLE WITH DEMENTIA

The following members participated in the group interview:
- Helen Rochford Brennan (Ireland) Chairperson
- Alv Orheim (Norway) Vice-Chairperson
- Chris Roberts (UK – England, Wales and Northern Ireland) Vice-Chairperson
- Helga Rohra (Germany)
- Nina Balackova (Czech Republic)
- Carol Hargreaves (UK – Scotland)
- Karin Gustafsson (Sweden)
- Idalina Aguiar (Portugal)
- Markku Parkkisenniemi (Finland)

Four care-givers supporting these members (Jane, Lars, Nelida and Berit) also contributed actively to the discussion. Ana Diaz, Project Officer, Alzheimer's Europe took detailed notes of the discussion. An audio recording of the session was also made but, due to the tight timescales and the degree of details of the notes made by Ana, it was decided not to transcribe the full discussion, which lasted a total of three hours, including breaks and presentations. The write up was analysed, again using the thematic headings of the four cornerstones model.

We include overleaf:
- The information we sent out to participating members of the group one week before the meeting;
- The slide deck we used to structure this discussion.

Information to go out to members of the European Working Group of People with Dementia about the session on the morning of Tuesday 13th December

Who are we?

Imogen Blood   and Steve Milton

Imogen runs the independent research consultancy, **Imogen Blood and Associates**.

We work with governments and services to make services and policies fairer and better.

We are passionate about using research to make sure that diverse (and often unheard) voices are at the heart of this.

You can find out more about us at: www.imogenblood.co.uk

Steve is a director of **Innovations in Dementia** - a social enterprise focused on the voices of people with dementia. Innovations are probably best known for the DEEP project - a network of groups of people with dementia in the UK.

You can find out more at www.innovationsindementia.org.uk

What are we doing?

We are doing a piece of work for the English Government (Department of Health) as part of the European Union's Joint Action on Dementia.

This involves drawing together what is already known about how to create 'Dementia Friendly Communities' across Europe and beyond.

Our findings will inform a toolkit and some pilot projects across Europe on Dementia Friendly Communities in 2017.

We hope that people involved in developing Dementia Friendly Communities across Europe will read our report and use it to help them:

- Understand what makes communities 'dementia friendly' (and what doesn't);
- Come up with ideas of actions they might take in their communities;
- Involve people with dementia in this work in a meaningful way; and
- Understand whether what they are doing is actually making a difference to the quality of life of people with dementia and those who support them.

Our report needs to be written by Christmas.

How have we gone about this?

So far, we have:

- Met with two small groups of people with dementia (in Redditch and Bradford in the UK) to hear what they think makes a community 'dementia friendly';

- Found and read over 70 reports and articles relevant to 'Dementia Friendly Communities'. We have been particularly interested in what has been learned so far from these projects, what works well and what difference it makes to the lives of people with dementia;

- Sent out an online survey to national representatives in each of the European countries and asked them to send these out to anyone with an interest in Dementia Friendly Communities. These have asked people what makes their communities accessible/ inaccessible and what has been done to improve this. We have had over 60 responses; and

- Interviewed around 20 people involved in Dementia Friendly Communities across Europe. We have done most of these by phone, but we have been out to visit some local projects in England and this has included meeting people with dementia who are involved.

Why are we coming to your meeting?

We are looking now at what we have learned from all this and starting to write it up into a report.

We are really keen to share some of the headlines with you and see whether these fit with your experiences and views and whether you have things to add.

We are particularly keen to feed in your practical advice as to how people with dementia can be engaged at the start and heart of Dementia Friendly Community initiatives.

We are really delighted that you are setting aside the morning session of Tuesday 13th December to help us in this.

We will be arriving at the hotel the evening before and hope to meet as many of you as we can over dinner on Monday evening and/or breakfast and lunch on the Tuesday. This should give us a chance to get to know each other better and to hear your views in a more informal setting.

What will we do during the session?

Part 1: What are your experiences in your local community?

We would like to spend the first part of the session hearing about your individual experiences and (where you feel in a position to do this) those of others with dementia about the accessibility of YOUR community.

Questions will include:

1. **What helps you (and/or other people with dementia) to take part in day-to-day life in your local area?**

2. **Which people or organisations help this to happen?**

3. **What stops you (and/or other people with dementia) from taking part in day-to-day life in your local area?**

4. **Which people or organisations can remove these barriers?**

Part 2: Sharing key messages from our project

We would then like to share with you some of the key messages from our project.

We will present a slide with one or two bullet points on it; explain what we mean by this then pause to find out whether you think this resonates with your experiences.

We expect to share between 4 and 6 of these headlines depending on the time.

We haven't yet decided on these headlines (as we will be working on them between now and then!) but an example might be:

"A 'dementia friendly community' is more about the people than about the physical environment"

Part 3: Practical examples of how best to involve people with dementia in 'Dementia Friendly Communities'

Have you been involved in creating 'Dementia Friendly Communities'? If not - you will have been asked to be involved in dementia-related discussions.

We wondered if you might think of two examples:

- When your engagement went well - and why…
- When it did not go so well, and why…

Given these experiences, what advice might we give to those planning to set up Dementia Friendly Communities about what they need to do to make sure people with dementia are involved at the heart and from the start?

We will take a 30 minute break in the middle of this session.

If everyone is happy with this, we will record the session so we can capture your views accurately.

We hope to use some quotes from the discussion in our report to make sure that the voices of people with dementia speak out through it. However, we will not say which individual said each quote. Do let us know if there is anything you would rather we did not include.

We really look forward to meeting you in Brussels.

If there are any questions before the meeting, you can get in touch with us at:

imogen@imogenblood.co.uk
steve@myid.org.uk

Presentation to European Working Group

Department of Health

Co-funded by the Health Programme of the European Union

Dementia-Friendly Communities: Evidence Review

European Working Group of People with Dementia, Brussels

Imogen Blood & Steve Milton

Tuesday 13th December, 2016

ImogenBlood & Associates

iD Innovations in Dementia

EU Joint Action on Dementia

Dementia Friendly Communities
(Work Package 7)

Evidence Review → Toolkit → Pilots

Our key questions

- What is a 'Dementia Friendly Community'?

- What do we know about what works – from across Europe and beyond?

?

So far, ……..

- 2 groups of people with dementia (in UK)

- 70 relevant reports and studies

- 60 responses to our online survey

- 20 interviews (and a few visits): range of stakeholders, projects from 7 EU countries

What helps you take part, day-to-day ?

My neighbourhood

Taking part in day-to-day life:
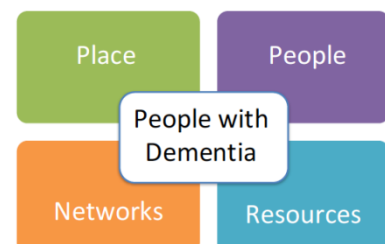
Which people or organisations help you?

What stops you taking part?

STOP

Which people or organisations can remove these barriers?

The framework we are using for our report

Place | People

People with Dementia

Networks | Resources

People

Improving people's understanding of dementia so as to change their attitudes is the most important part of trying to make a community 'dementia friendly'.

Place

Its about making normal everyday places accessible. This involves thinking about the buildings and public places we all use, but also about transport and written information.

Networks

Health and social care are only part of the network needed: leisure, culture, shops, banks, police, fire, etc also need to be involved....but how do we make sure people with dementia are part of the alliance?

Resources
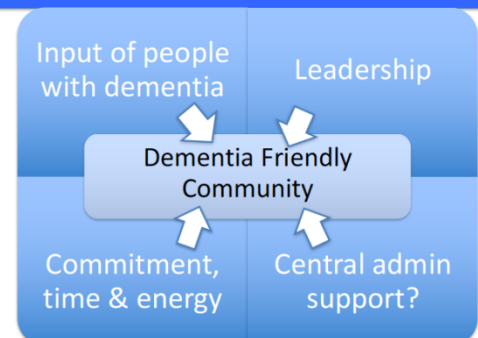
What works in engaging people with dementia?

Your positive experiences of being involved: why did they work well?

When involvement did not go so well?

What is the learning here for people trying to set up or sustain Dementia Friendly Communities?

Thank you!!

Our full report and accessible summary should be available early in 2017 and we will send you them. In the meantime.....

HOW WE DEVELOPED THE DEFINITIONS, MODEL AND PROPOSED INDICATORS

The online survey feedback in relation to the four existing definitions was analysed, drawing out key themes in the response to each definition. These were synthesised, along with data from the interviews and group discussions in which definitions had been specifically discussed and along with the key messages about the core values and objectives of a DFC drawn from across the data sources. From this, a list of key principles and considerations for a definition was identified. The team them drafted the definition with the intention of responding as far as possible to key definitions, within a succinct form of words.

In the first draft of the report, the team proposed a list of the core features of and essential participants in a 'good' DFC, based on the evidence reviewed. The senior researchers subsequently met and checked alignment with the key components of other existing models (such as the Alzheimer's Society England's recognition process (Alzheimer's Society and DAA 2015), the British Institute of Standards (BSI 2015) and the EFID (Williamson 2016) review). From this, we distilled and developed the visual model.

In the first draft of the report, the team proposed a set of indicators for each of the four 'cornerstones' of People, Place, Networks and Resources, based on the evidence reviewed and on our appraisal of the methods used in existing DFC evaluations.

We have subsequently tightened up the structure of these in order to align them to the World Health Organisation's work to develop Age Friendly indicators.